

# **MASK: MIRROR: MEMBRANE**

The photograph as a mediating space in clinical and creative pain encounters

## **VOLUME 1: THESIS**

(All figures are placed in volume 2 for reference in conjunction with this thesis)

**DEBORAH PADFIELD**

Slade School of Fine Art, University College London

Ph.D. Thesis

2013

# **DECLARATION**

I Deborah Padfield confirm that the work presented in this thesis is my own.  
Where information has been derived from other sources, I confirm that this has  
been indicated in the thesis.



# ABSTRACT

Pain is difficult to communicate and constrict into the verbal or numerical scales commonly used. This thesis explores how photographic images can expand pain dialogue in the consulting room to include aspects of experience frequently omitted using traditional measures.

It draws on material generated by the **face2face** project, a collaboration with facial pain specialist Professor Joanna Zakrzewska and clinicians and patients from University College London Hospitals. The project has many strands: art workshops for clinicians and patients to attend together; the co-creation of photographs with facial pain patients reflecting their experience at different points in their treatment journey; the creation of an image resource developed as an innovative communication tool for clinical use; and an artist's film focusing on doctor-patient dialogue and the role of narrative.

The thesis argues that photographs of pain placed between patient and clinician can trigger more negotiated dialogue in the consulting room. It presents the co-creation of 'pain portraits' with pain sufferers as part of a Fine Art practice, extending the boundaries of what is considered Fine Art by shifting the power-dynamics inherent within the act of portraiture. Through shared control of the lens and a negotiated aesthetic, pain sufferers retain control of how their pain is visualised, instead of being on the passive receiving end of a medical/photographic gaze. The thesis explores and questions the specificities of photography as a particularly apposite medium for this work. It validates and makes visible the invisible subjective experience of pain, addressing its incommunicable nature. Semiotic and metaphoric analyses of the material reveal the possibility of a developing inter-subjective and trans-cultural iconography for pain. The thesis aims to demonstrate that not only is medicine capable of providing new material for the gallery space, but art is capable of bringing new knowledge into the consulting space.

## **BRIEF OUTLINE OF CONTENTS:**

**PAGE:**

### **VOLUME 1: THESIS**

TITLE PAGE	1
DECLARATION	2
ABSTRACT	3
CONTENTS	4
ACKNOWLEDGEMENTS	14
INTRODUCTION	21
<b><i>MASK</i></b>	33
CHAPTER 1	35
<b><i>MIRROR</i></b>	107
CHAPTER 2	109
<b><i>MEMBRANE</i></b>	189
CHAPTER 3	191
CONCLUSION	262
NOTES	276
BIBLIOGRAPHY	290

### **PRACTICE RELATED SUBMISSION**

*(Placed in pockets inside back cover)*

CD Documentation of ***face2face*** project

DVD of film ***duet for pain***, 11'40"

### **VOLUME 2: IMAGES**

All images are contained in Volume 2 for reference

### **VOLUME 3: APPENDICES**

All appendices (A to V)

<b>FULL TABLE OF CONTENTS</b>	<b>PAGE</b>
<b>VOLUME 1: THESIS</b>	
<b>INTRODUCTION</b>	21
<b>AIMS</b>	21
Research Questions	
Background	
<b><i>FACE2FACE</i></b>	24
<b><i>Face2face</i></b> outline:	
Summary of <b><i>face2face</i></b> methodology:	
Facial pain and the portrait	
<b>OUTLINE OF THESIS</b>	28
Complexities of pain and limitations of current medical framework	
Collapsing physical and emotional pain	
Translation	
The photograph that wasn't taken	
<b><i>MASK</i></b>	33
<b>CHAPTER 1: THE MEDICAL PERSPECTIVE</b>	35
<b>INTRODUCTION</b>	35
Acute v Chronic or Maladaptive Pain	
Visibility/Invisibility and the doubt of others	
What is pain?	

Chronic pain and its position at the margins of medical practice and communicability

Illness narratives as stories

Pain and/or Suffering

## **CHANGING THEORIES AND CONSCPETUALISATIONS OF PAIN** 44

A brief history of pain

Contemporary medical pain theories

Contemporary medical pain representations, measures and their limitations

Rate your pain on a scale of 1 – 10

Examples of other medical studies using art to assess pain

Narrative medicine/ emotional disclosure

Rita Charon

Johanna Shapiro and John Sarno

## **COMMUNICATION – DIALOGUE – LANGUAGE** 64

Can pain be put into words?

Pain as generating language

Space between word and image

Effective two-way communication

## **FIGURATIVE LANGUAGE FOR PAIN** 73

Metaphor

Analogy

Simile

Metonymy

Catachresis

## **CHANGING METAPHORS AND SCHEMAS FOR PAIN** 79

<b>HISTORICAL METAPHORS FOR PAIN</b>	79
Ancient Schemas	
Humoural Theory	
Christian and religious frameworks	
Pain metaphors in the industrial age:	
Contemporary pain metaphors of military and germ warfare	
<b>LITERARY METAPHORS FOR PAIN</b>	89
Metaphors of sharpness: ice, needles, claws, spears	
Multimodal metaphors for pain	
Language as an extension of the self	
<b>VISUAL METAPHORS</b>	97
Perceiving the body via visual metaphor	
Pain as a surreal experience	
Materiality of visual metaphors	
Visual metaphor: engagement and interpretation	
The Pain Cards as visual metaphors with materiality	
<b><i>MIRROR</i></b>	107
<b>CHAPTER 2: THE PHOTOGRAPHIC PERSPECTIVE</b>	109
<b>INTRODUCTION</b>	109
Why use photography? Tagg and the specificities of the photographic medium	
Body and camera as space where darkness and light, interiority and exteriority meet	
The house of pain	
The wound: liminality between interiority and exteriority	

<b>REPRESENTATION</b>	112
Barthes and the photograph as indexical construct	
Semiotics	
Connotation and denotation	
'Authenticity' and the Photograph: Sontag, Burgin, Bate and Berger	
<b>INTERPRETATION</b>	121
A space for ambiguity	
Barthes' third meaning	
Reversing the power dynamic through control of the lens: Spence, Foucault, Tagg	
Spence	
Autotherapy and the mirror	
The intruder	
Foucault: power-dynamics and the ' <i>medical gaze</i>	
<b>THE PHOTOGRAPHIC PORTRAIT</b>	130
From where the gaze starts: the Face	
The photographic exchange/encounter	
<b>THE BEGINNINGS OF PORTRAIT PHOTOGRAPHY IN 19 C. MEDICAL DISCOURSE</b>	134
Photography as part of the armoury of science: evidence gathering	
The promise of 'objectivity'	
Issues of power in the hands of 19 c. doctor-photographers	
Jean Martin Charcot	
Dr G. B. Duchenne de Boulogne	
Dr Hugh Welch Diamond	
Staging and honesty of the exchange	

Pressure to 'perform' or enact identity projected by others  
Photographs as a means of eliciting narrative: photo-elicitation, photo-therapy, photo-voice

**PHOTOGRAPHY AND PAIN IN FINE ART** 155

Jo Spence

Steve Dwoskin and Bob Flanagan

Grosz: a phenomenology of subjectivity, subjectivity inscribed within the body

Making sense of pain: re-making a coherent sense of self

Alexa Wright: disruptions to the self, phantom limb pain

Visibility

**PHOTOGRAPHIC PORTRAITURE WITHIN FINE ART** 166

Alexa Wright

Dryden Goodwin

Helen Sear

Deborah Padfield

Portraits of pain

Co-creative photographic process

Photographing pain

Photographs as triggers to dialogue: the PAIN CARDS

Vanitas Cards

Film

**MEMBRANE** 189

<b>CHAPTER 3: ANALYSIS</b>	191
<b>INTRODUCTION</b>	191
Methodology	
<b>STRAND 1: ART WORKSHOPS</b>	194
Workshop aims	
Workshop methodology	
Analyses of workshop material (For full analysis see Appendix M)	
<b>STRAND 2: CO-CREATED PHOTOGRAPHS</b>	195
Aims	
Key notions	
Methodology	
Translations and relations	
Literal and symbolic	
Predominant metaphors and their relationship to categories identified by Biro and Semino	
Case Studies	
I3 Trigeminal Neuralgia pain – relived by surgery	
I2 Chronic facial pain – for which there is no cure	
Atypical metaphors/ ‘outliers’	
W5: Resists reflecting movement from high to low pain – spirals around pain	
Interpretation	
Pain as a shadow	
Semiotic interpretation	



Aims

Methodology

Key issues

The consultation as a discursive space: contestation

Pain cards as relational objects

Alfred Gell: The Index

Analysis

Quantitative findings:

Image selection

Evaluation forms post consultations

Patient quantitative results

Clinician quantitative results

Patient qualitative results

Clinician qualitative results

Analysis of recorded consultations

Clinician H

The space inbetween

The cards' agency

Cards as a shared reference point

Images revealing emotion

Cards eliciting new information

Increase in rapport

Clinician A

Clinician K

Clinician D

<b>CONCLUSION</b>	262
-------------------	-----

Pain treatment as a 'human right': grasping the moment

Aims and conclusions of the thesis

Reaching towards toleration of ambiguity and uncertainty

Towards an equal mutually beneficial exchange

What can art offer medicine?

The future: *Pain: Speaking the Threshold*

And finally...

<b>NOTES</b>	276
--------------	-----

Introduction	276
--------------	-----

Chapter 1	277
-----------	-----

Chapter 2	282
-----------	-----

Chapter 3	288
-----------	-----

Conclusion	No notes
------------	----------

<b>BIBLIOGRAPHY</b>	290
---------------------	-----

**VOLUME 2: IMAGES**

List of Figs.	Figs. 1 - 95
---------------	--------------

## **VOLUME 3: APPENDICES**

<b>A:</b> Patient Consent	i
<b>B:</b> Photographic release	ii
<b>C:</b> Clinician Consent	iii
<b>D:</b> Patient Questionnaire	iv
<b>E:</b> Clinician Questionnaire	x
<b>F:</b> Favourable Ethics Opinion	xvi
<b>G:</b> NIHR CRN Registration	xxii
<b>H:</b> UCL Data Protection Registration	xxiv
<b>I:</b> Patient Information Leaflet for Recorded Consultations	xxv
<b>J:</b> Patient Information Leaflet for Patient Journey & Workshops	xxvii
<b>K:</b> Clinician Information Leaflet	xxix
<b>L:</b> NHS Protocol	xxxi
<b>M:</b> Analysis of Workshops: Quantitative & Qualitative	L
<b>N:</b> Summaries of Workshop Session Plans	Lix
<b>O:</b> Workshop poster to attract patients	Lxvi
<b>P:</b> Workshop Evaluation Form examples: first four pages of transcript	Lxvii
<b>Q:</b> Clinician invitation/advert to participate	Lxxi
<b>R:</b> Advert for UCLH Trust Open Day	Lxxii
<b>S:</b> Evaluation Forms: completed examples from Patient Journey	Lxxiii
<b>T:</b> Graph of most frequently selected images	Lxxxvi
<b>U:</b> Reviews of Mask: Mirror: Membrane: Bmj and the Lancet	Lxxxvii
<b>V:</b> Publications:	
<i>International Journal of Surgery</i>	XCi
<i>Health Journal</i>	XCix
<i>Pain News</i>	CXvi

# ACKNOWLEDGEMENTS

There are many people I would like to thank, without whom these projects and this thesis would not have happened, and many more who there is not space to name.

First of all I would like to thank all the pain patients and clinicians who participated in both the ***perceptions of pain*** and the ***face2face*** projects. In particular I would like to thank the pain sufferers who worked intensively with me to co-create images of their pain; in ***perceptions of pain*** this was: Rachel Brooks, Frances Tenbeth, Patrick Dixon, Helen Lowe, Stephen Dwoskin, Nell Keddie, John Pates, Rob Lomax, Penny Harding, Robert Ziman-Bright; in ***face2face*** this was: Liz Aldous, Ann Eastman, Alison Glenn, Chandrakant Khoda, and Yante . Their generosity, creativity and insights have made this research and associated exhibitions possible. I would also like to thank Francine Ozarovsky for generously allowing me to film an interview with her talking poetically and personally about her experience of pain and even more courageously for allowing me to use extracts from it within the films *facing pain* and *duet for pain*.

I owe an enormous debt of gratitude to my supervisors who have supported and inspired me throughout this whole process, and without whom I could never have got through it: Dr Sharon Morris, my primary supervisor, who I cannot thank enough for her continuous support, sensitivity and encouragement, particularly when the going was tough, and for her intellectually astute and perceptive comments on my developing draft helping me to shape and structure it. I have valued her creativity, vision and language skills enormously, and her ability to see clearly when I felt utterly confused. I am delighted that she is willing to be PI on a future project which builds on this doctoral research; Prof. Joanna Zakrzewska, my second supervisor, without whose energy and commitment the ***face2face*** project, (on which this research is based), simply could not have happened. More than almost any other clinician I have come across, she believes in the value of images to facilitate doctor-patient communication and of eliciting significant narrative within pain management encounters - hers has been a truly whole hearted involvement. This type of work and research cannot happen without the support of such clinicians and its

validity and potential use would have been limited without her integral involvement. I have much enjoyed our discussions on pain and images and benefitted from her wealth of experience and knowledge as a world leader in this area and the time she has put aside for this project alongside an incredibly heavy clinical schedule and personal support she has given me. I am delighted that she too is willing to be co-PI on the new project going forward; Dryden Goodwin, my practice supervisor, whose ingenuity, creativity, skill and imagination have influenced my steps into film making and helped me develop as a creative practitioner, I have valued our discussions enormously and the time and commitment he put aside when we met to really engage with the work. His observations were always perceptive and inspired; Dr Amanda Williams, who has constantly supported me through this process and provided space to think about the process, my relationship with the projects' participants, its effects on me, my aims and desires for the work. Despite an incredibly heavy workload she was never too busy to see me, was always sensitive and insightful and enabled me to see things I would never otherwise have been aware of. She kept not only me safe, but the people I was working with, providing an informed and perceptive space within which to reflect and discuss the process of working with people coping with such high levels of suffering. I am incredibly grateful to her and will miss our sessions. I would also like to thank my previous supervisors for their support before leaving for jobs further afield; Prof. John Aiken who I always enjoyed meeting and discussing work with and who supported me hugely including making the trip down to the Menier Gallery for the opening of the exhibition, and Professor Penny Florence for admitting me in the first place, for suggesting I spend an interdisciplinary year in Anthropology before coming to the Slade, which was a stroke of inspiration, and for her insightful comments and belief in my work, which gave me huge encouragement; Prof. David Napier, for accepting me onto the medical anthropology courses when I had no previous experience of anthropology and opened my eyes to aspects of this research I could never have come across on my own and greatly informing my approach to the research; Professor Suzanne Kuechler whose lectures were fascinating and who continued to discuss the project with me after I left Anthropology despite heavy work commitments, whose comments I value enormously and which have informed my recent analysis of the work. I have also benefited from the support of previous tutors from Middlesex University, in particular Tansy Spinks and Penny Machin for on-going support and friendship. I am grateful to the many arts and medical humanities students, in particular those at King's and Imperial

Colleges, London who have responded to the work in such a lively way and contributed to my thinking about it, and to Giskin Day and Michelle Cussens for inviting me to work with their students, who continue to open my eyes to new facets of the work.

I have also benefitted from the skills, sensitivity, creativity, motivation and commitment of Helen Omand who has supported me throughout this whole process. At moments of crisis she has always been there and calmly helped sort through the work that needs to be done, never quitting until the work is finished and using her logical and organisational skills in addition to her creative and artistic ones. I have benefited from her editing skills with my inroads into film and from her design and people skills with her help on the project and in promoting it. I am delighted she will be lending her expertise to the new project. I would like to thank my cousin William Abbott for his help with the tables and statistics and interest in the project, as well as Maria Naveiro who supported me sensitively and constantly at the beginning of the project and whom I am indebted to for transcribing many of the evaluation forms and interviews. It would have been impossible to carry out a project of this type without skilled administrative assistance and I am very grateful for the time and skill Monica McKee-Vincent put into the **face2face** project, the organised filing of all the consents and paperwork, contact with the participating patients including frequent phone calls and sorting out administrative problems as they arose, always with a friendly face. I am also grateful for the hard work of Hawwa Almaghrabi who was the first administrator on the project before going on to study social work. She helped in so many ways in those early months, which enabled the project to get started, going to any lengths to get a job done with compassion and humour.

I am grateful to all of those who took part in the **face2face** associated events: Alistair Adams PRP, Dr Emma Chambers, Dr Brian Durrans, Gina Glover, Professor Sue Golding, Rosy Martin and Jane Wildgoose who gave their distinct perspectives and added greatly to the value of the symposia and visitors' experience of the exhibitions. I would like to thank all those who made the exhibitions possible, particularly: Stuart Davie, Damian Hebron, Angus Braithwaite, Thomas Treacher, and Karl Otto Karl, who I am also grateful to for his assistance on the project and help with digital editing which greatly enhanced the outcomes. I was very fortunate to have the expertise of Elaine McLaren whose graphic design helped promote the exhibitions and whose

friendship and skills I value highly, even extending to night time discussions about last minute exhibition text panels.

I will always be grateful to Dr Charles Pither, with whom I collaborated on the first project ***perceptions of pain*** and where all this could be said to have begun, for his enthusiasm for this approach and insightful discussions. I am also grateful to Farah Janmohammed who helped analyse the feasibility study for ***perceptions of pain***, which validated the development of the research and to Prof Brian Hurwitz for leading the research on the ***perceptions of pain*** project and for all subsequent encouragement and friendship.

I am grateful to Ruth Richardson for allowing me to quote from her papers and to David Biro for his support for and analysis of this work, continuing friendship and allowing me to quote from his writing on metaphor; also to Dr Cary Brown for inviting me to present the work in Alberta Canada and for her astute observations on the value of my work in her chapter on pain, Prof Elena Semino for her incredibly insightful analysis of my work and enthusiasm for it, to Minae Inahara for her perceptive analysis of the ***perceptions of pain*** images and observations on pain and phenomenology, to Kathleen Lennox for inviting me to present the work and meet her colleagues which included Minae, and for being generally supportive, as well as Prof Tom Cole and Dr Nathan Carlin for their hugely enthusiastic and erudite analysis of the ***perceptions of pain*** work in their chapter on *Maldynia as Muse*, and their continuing correspondence, and to Prof Joanna Bourke for all the stimulating conversations we have had in which I have benefited from her wealth of expertise and knowledge and for her support for the work including commissioning me to show the film at the Birkbeck conference at the Wellcome Trust, *Pain and its meanings*. I am also grateful to Dr Louise Hyde and Dr Carmen Mangion from the Birkbeck Pain Project for their support for the project and research and conversations around pain, which were hugely stimulating.

I would particularly like to thank my examiners, Prof Alan Bleakley and Dr Helen Sear for the incredible commitment they gave to reading and commenting on this thesis and associated practice. I feel very fortunate in my choice of examiners, I could not have asked for two more skilled, rigorous or generous people with which to discuss the work, and the thesis has benefitted hugely from their observations and suggestions. I would like to thank Prof Bleakley for his

detailed proof-reading which must have taken considerable time, and to Helen Sear for her insightful comments on the film and for spending time with it.

I would like to thank my peer group of students at the Slade and the Slade staff for the stimulating atmosphere in which I have been able to make and reflect on the work. Their comments and discussions have helped its development, in particular I am grateful for the observations of Jayne Parker on the films and Prof Susan Collins for the support she has lent to the work and to me. I am very grateful to the administrative staff at UCL and the Slade, in particular Diana Goforth (anthropology) and Lou Adkin (Slade) and Jennifer Jennings (Slade) and to the arts and humanities librarian Elizabeth Lawes who has been incredibly tolerant of my inability to find my way around technology and for her prompt replies to my queries; also to the technical staff, Michael Duffy, John Bremner, Alan Taylor and Mick Farrell, who have helped me overcome some of the challenges of technology and physical space. I am grateful to the UCL disabilities department who have provided the support which made this research process possible and the students who supported me: Liza Cucco, Gabby Beveridge, Vishala Parmasad and Annora Yet-Dessus.

I am also grateful to the many organisations and their staff who supported the **face2face** project and associated exhibitions. These are: Eastman Dental Hospital, UCLH Education Centre and UCLH NHS Foundation Trust, UCLH Arts, Paintings in Hospitals, the Menier Gallery, London Arts in Health Forum (LAHF), the National Portrait Gallery, and the Slade School of Fine Art, UCL. Also to Guy Noble, arts curator UCLH arts who has given immense support to me and to the work, and who invited me to show the work in the UCH street gallery and is currently storing the photographs, and for all his help on the shows, and to Professor Aidan Halligan who made the rooms at the UCLH education centre available to us for the recorded consultations and art workshops, who agreed to open the UCH exhibition with an inspiring introductory talk and who has given me huge personal encouragement.

I am also grateful to those who funded both the **perceptions of pain** and **face2face** projects, without whom they could not have happened: Sciart, Arts Council England, Guy's & St Thomas' Charities, UCLH arts, UK CRN, Derek Hill Foundation Trust, and in particular the AHRC for funding which allowed me to carry out the research. I am also grateful to the UCL Graduate School whose awards enabled a study trip to Paris to view the Duchenne, Charcot and



Bertillon archives, and to present the work at the 100<sup>th</sup> Indian Science Association Congress in Calcutta this year (2013). I am also grateful to UCL for awarding me the Provosts Award for Public Engagement, in the research student category this year and to UCL CHIRP for awarding me a fellowship to continue to build on this doctoral research, allowing it to develop and benefit from new exchanges with a team of highly stimulating and experienced colleagues. This is a really exciting prospect I could only dream of.

I would like to thank my friends and family for all their encouragement throughout this period and in particular my extraordinary husband, Graham Treacher, without whom I could not possibly have completed the work or research. He has listened to me reading most of this thesis out loud, made insightful comments on draft after draft, made me value it when I felt despondent, and continues to inspire me with his vision, humour and humanity.

*Come with me; for my painful wound  
Requires thy friendly hand to help me onward.*

(Sophocles, *Philoctetes*)

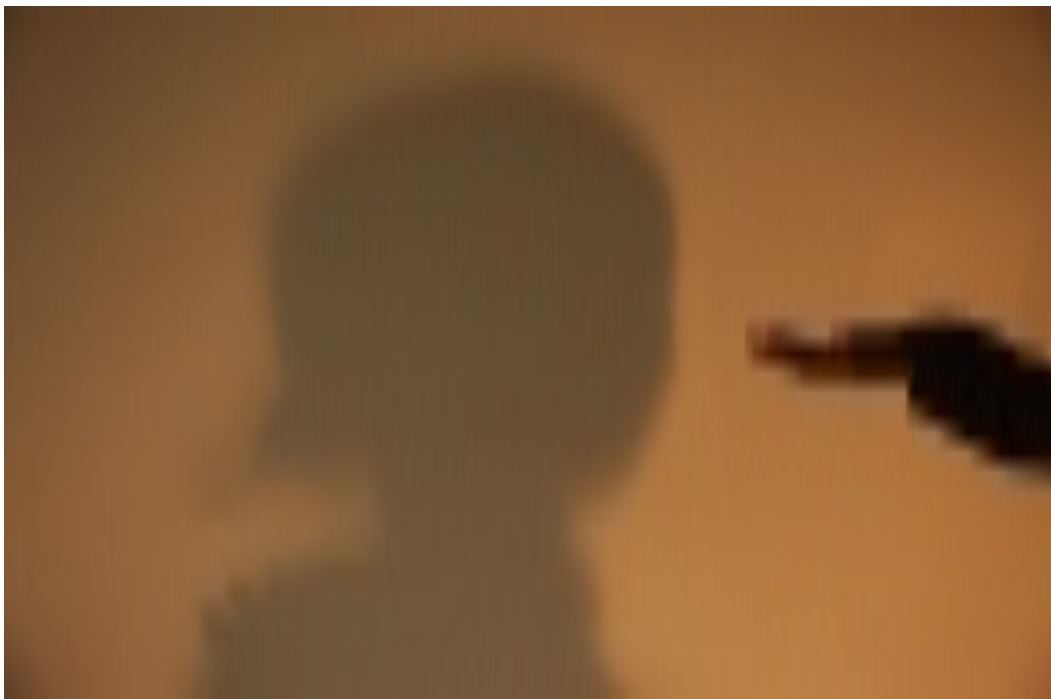


Fig. 2

# INTRODUCTION

## Aims

The overall aim of my thesis is to research the impact of photographic images and image-making processes on doctor-patient pain dialogue and mutual understanding and rapport in chronic pain consultations.

It draws primarily on material from the **face2face** project (2008-2013), a collaboration between myself and consultant facial pain specialist Professor Joanna Zakrzewska, to support its main hypothesis: that aesthetic spaces can allow access to other ways of 'knowing' and communicating pain.

Where relevant to its argument it also draws on other work I have done in this field including an earlier collaboration with Dr Charles Pither, ***perceptions of pain*** (2001-06)<sup>1</sup> and a co-created film for the Science Museum's Exhibition *Painless* (2012)<sup>2</sup>.

Much of this work aims to make visible that which is invisible, give form to and explore the space between selves, subjective experience and objective measures, fine art and medical language, and text and image, in order to better understand and communicate pain. Communication comes from '*communicare*' in Latin meaning to '*share*' (Biro 2010). The materiality of the visual metaphor allows a different type of sharing to take place. I would add that the ambiguity of the visual metaphor also encourages negotiation and sharing. The thesis explores the agency of photographs when placed between clinician and patient in the consulting room to; build relationships, create a membranous space through which two-way dialogue can flow, and rebalance power relations by returning control of illness narratives to patients.

## Research Questions

Citing Scarry's seminal position that pain resists communication through resistance to language, (Scarry 1985) the thesis argues that a visual language can provide an alternative means for effectively communicating pain. It asks whether a series of photographic images of pain co-created with pain patients, could provide an alternative language for pain improving doctor-patient dialogue in the medical setting? It explores and questions the specificities of photography as a particularly apposite medium for this work and asks could these photographs generate an expanded and richer vocabulary capable of bridging the space between the person in pain and the person witnessing or treating it?

## Background

Pain is notoriously difficult to communicate (Hurwitz 2003, Wall & Melzack 1984, Semino 2013). Inadequate communication has been cited as one of the causes of poor or inadequate treatment of pain (Kimberlin et al 2004, Yates et al 2002, Padfield et al 2010). It has been the subject of research and debate throughout history, but our ability to understand or even define it remains incomplete. The thesis focuses mainly on chronic as opposed to acute pain.<sup>1</sup> The International Association for the Study of Pain (IASP 1979) describes it as:

*an unpleasant sensory and emotional experience associated with actual or potential damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences relating to injury in early life.*

The challenge is to create a visual language capable of capturing and communicating the subjective and emotional nature of pain, which evades constriction into traditional measure such as 'describe your pain on a scale of 1 to 10'. This is particularly relevant where pain has existed for many years and become part of a complex picture. It is also to expand existing metaphors for conveying pain which currently focus on notions of injury and damage, even when there is no remaining evidence of tissue damage or lesion.

American Physician and academic David Biro (Biro, KCL Lecture 25<sup>th</sup> October 2012, Birkbeck Lecture 26<sup>th</sup> October 2012) argues for an expanded definition of pain, to that advocated by the IASP, redefining it as: *'the aversive feeling of injury to one's person and the threat of further potentially catastrophic injury'*. He argues this would reduce semantic confusion around pain, and provide a better framework for managing patients, encouraging new ways of treating them by removing a distinction between actual and perceived damage between physical and emotional pain.

The texture and form of the art objects created during both **face2face** and **perceptions of pain**, aim to act on our bodies as well as our perception so that the senses as well as the mind are drawn into a metaphoric and imaginative space. We don't just conceptualise pain's meaning, we experience its meaning. This brings us much closer to the lived experience of pain. Could these visual representations of pain therefore help us formulate a broader definition of pain, and highlight aspects of pain experience we need as a society and as individuals to address?

In the general population 15 – 20% of people suffer from chronic pain (Blyth et al 2001, McFarlane et al 2001, Padfield & Hurwitz 2003). A Government Survey for the NHS in 2011 reported 34% people in the UK as suffering from chronic pain. Pain therefore not only creates a huge burden of suffering for the individual, but a heavy financial burden for society. If images can allow significant aspects of pain which need to be discussed to surface more immediately in the consulting room and a better rapport to develop between clinician and patient, then time, money and suffering can be reduced in the future. Medical educationalist and psychologist, Professor Alan Bleakley (2006, 2011, 2012, Marshall & Bleakley 2013) has long argued for the democratisation of medical dialogue as a means of improving medical practice and reducing poor treatment and medical mistakes. Intervening in the dialogue through the use of images, is one means of effecting this, and a key aim of the project.

## **Face2face**

The **face2face** project was made possible through an artist's residency within the facial pain management teams at UCLH. It is important to re-iterate at this point that the research would not have been possible, and its validity severely limited without the co-operation of the pain management team at UCLH, the creativity and involvement of participating patients and in particular without the support and commitment of my clinical collaborator and second supervisor, Prof. Joanna Zakrzewska.

I will give a brief outline of the project as a backdrop against which to read the rest of the thesis and refer back to when necessary.

### **Face2face outline:**

- 1) Art workshops for clinicians and patients to attend together delivered in association with the National Portrait Gallery (NPG) between October and December 2009.
- 2) The co-creation of images of pain with facial pain sufferers at different points of their journey as they progress through pain-management.
- 3) The integration of a selection of these images into a pack of Pain Cards for clinical use.
- 4) Research into the effect of using these cards within NHS Pain Consultations, video recording their clinical use by a variety of different pain specialists
- 5) The creation of a new film exploring experiences of having and treating facial pain.
- 6) The development and delivery of a new exhibition reflecting the process and outcomes, alongside interdisciplinary events, shown at the Menier and the UCLH Street Galleries, London, between July and September 2011.

A short summary clarifying each strand follows but a full description of the methodology can be found in the NHS Ethics Protocol in the appendices,

along with examples of other documentation such as clinician and patient information sheets, evaluation forms, and promotional material. (pp xxxi, xxv, xxvii, xxix, Lxxiii, Lxvi, Lxxi)

### **Summary of *face2face* methodology:**

- 1) The workshops were co-led by myself and artist Mark Woodhead from the National Portrait Gallery, assisted by Helen Omand. They involved a mix of looking at and discussing images both within the gallery's unique collection of portraits, and through slide projections of relevant portraits not in their collection, along with quick drawing, painting and photographic exercises. The aim of the workshops was to bring together patients and clinicians experiencing or treating pain in an environment outside the usual clinical setting to share experience and promote discussion. Session plans for the four workshops are included as appendices, see page Lix. All of the workshops were audio -recorded and transcribed. Participants were given evaluation forms to complete at the end of each session, the results of which are analysed in Chapter three, a sample of which can be found in the appendices on page Lxvii.
- 2) A series of 1:1 photographic workshops between myself and facial pain sufferers were held with the aim of co-creating images which as closely as possible reflected their unique experience of pain. The co-creation process with patients is described in detail in chapter two, see page 175. All the sessions were audio-recorded. An important change from the ***perceptions of pain*** project was that the ***face2face*** workshops spanned the duration of management, so that I worked with patients before, during and after treatment/management. This meant that the image-making process instead of leaving patients trapped within one image of pain at its worst, both contributed to and reflected changes in patients' experience of their pain while going through treatment/management. It allowed for transformation.
- 3) A selection of the co-created images, was used to develop a pack of '**PAIN CARDS**'. Additional images were also used from the earlier project ***perceptions of pain*** to broaden the range of pain represented. The pack contains 54 photographic images depicting different qualities, characteristics

and intensities of pain. Laminated and measuring 6" x 4" they resemble a pack of large playing cards. They can be relatively easily leafed through and laid out on a desk in different combinations to reflect different narratives and trigger different dialogues. The cards have been piloted within the pain management teams at UCLH and their effect as an intervention, analysed in chapter three (see page 218). They are offered as a new and original communication tool for use within pain medicine.

- 4) Pain Clinicians from a variety of specialities, from surgery to homeopathy, volunteered to pilot these **PAIN CARDS** within their clinics, and to move them to a designated consulting room at the Education Centre UCLH where they could be unobtrusively filmed. All participating clinicians and patients had signed written consents after receiving information leaflets (examples of which are included in the appendix, see pages I, iii, xxv, xxvii, xxix) but the discrete nature of the cameras allowed us to achieve as near as possible normal consulting conditions as participants soon forgot them. The aim was to explore the ways in which the photographs were functioning within a medical consultation, and the impact they had on content, language, rapport and interaction. The results have been entered onto spreadsheets available within the appendix and a sample analysed in chapter three. At a future date, using the expertise of professionals from other disciplines within and beyond medicine, a fuller analysis will be attempted which could provide insight into the role of art and the humanities in pain consultations such as has never been attempted before.
- 5) The film, ***duet for pain*** (2012), gave me a chance to author a piece of work, rather than co-creating it. The editing process inevitably raised ethical questions around the de-construction and re-construction of another's identity. It attempts to open up a space between medical and fine art research, collaging the voice of a pain sufferer and former model, with that of a pain specialist, exploring the space between perspectives. Re-filming and re-projecting its subjects within medical and photographic frameworks it aims to question the impact of both facial pain and photographic portraiture on construction of role and identity, while referencing ways in which we project on to or see ourselves reflected in another. It is a revision of an original film developed as a response to working within the pain-



management environment in 2011 called ***facing pain***, which explored the meaning of pain for those who experience or treat it, and the value of narrative within pain medicine. First shown at the Menier Gallery, London the film received excellent reviews from the medical, arts and general press, including the independent arts web pages, the *bmj medical humanities* blog and the *Lancet*.

*Padfield's film is a powerful clinician–patient dialogue and it is a remarkable first stage from which all the co-creators can move forward to making chronic pain less of a lonely, personal journey.* (Denna Jones, [www.thelancet.com](http://www.thelancet.com) Vol 378 July 30, 2011)

It has subsequently been shown at the Wellcome Trust, London, as part of the *Pain and its Meanings* Conference in November 2012, a collaboration between the Wellcome Trust and Birkbeck College.

- 6) The exhibitions and accompanying events were a chance to reflect on and create a dialogue between the different material produced, and to open it up to the gaze of the public, the arts, the clinical and patient communities. The exhibition entitled ***Mask : Mirror : Membrane*** was first shown at the Menier Gallery, Paintings in Hospitals, in July 2011 and subsequently at the Street Gallery in University College London Hospital.

Parallel events such as the artists' forum and interdisciplinary symposium are detailed in the accompanying CD presentation as part of my practice submission, which can be found inside the back cover.

## **Facial pain and the portrait**

It was through working in the facial pain environment that it became evident that not only could images and portraiture inform my understanding of facial pain, but an exploration of facial pain could inform my understanding of portraiture, its dynamics, its possibilities, and its boundaries. It demonstrated to me that images can help us negotiate between different perspectives – how we perceive and what we project onto 'the other' - how we navigate the space (actual and metaphoric) between us.

Issues of communication, already inherent to the pain experience are exacerbated when the 'canvas' normally used to express it, the face, is itself in pain. Unable to convey in a manner that others can comprehend, the face can become a contested and painful place, increasing the isolation of sufferers. It becomes either a **MASK** hiding the emotions behind it or a frozen **MIRROR** reflecting the projections of others. Ideally the face, like the communication process, is a flexible **MEMBRANE** through which we interact and navigate the world. For those with facial pain this process often becomes broken, fractured and disjuncted. What should allow fluid movement between the thresholds of selves, becomes a barrier separating one from another - through which the other is glimpsed but not seen, evoked but not touched.

## **OUTLINE OF THESIS:**

The thesis is divided into three chapters: **MASK**; **MIRROR** and **MEMBRANE**.

**Chapter 1: Mask**, examines past and present pain theories from a medical perspective setting out the limitations of current measures and available language to incorporate and reveal pain's subjectivity - your pain is not the same as my pain - or is it? It identifies pain's resistance to language and the need for an alternative (perhaps more primal?) language with which to facilitate improved communication in the consulting room. The ability of images to elicit significant, complex patient narrative is discussed along with their potential to complement current interest in 'narrative medicine'. Building on the available literature and work in the field, it proposes a group of pain images co-created with pain sufferers as a solution to some of these limitations, introducing a pack of **PAIN CARDS** as a new communication tool for use within NHS pain clinics.

**Chapter 2: Mirror**, examines the ethics and dynamics of exchange within photographic portraiture, exploring where these intersect and/or contrast with those of the medical encounter. Through the work of prominent photographic exponents in both medicine and fine art, such as Charcot, Duchenne and Diamond, through Spence and Martin to Sear, Borland, Wright and Goodwin, its possibilities and limitations are discussed. Analyses of their practices and of the specificities of the photographic medium contextualise the development of my process of co-creating photographs with pain patients as a central part of my

practice. An examination of the communication process and the role of narrative in pain experience inform the new film *duet for pain* (Padfield 2012). Semiotic and metaphoric analysis of the images produced reveal the possibility of a developing inter-subjective and trans-cultural iconography for pain. The section argues that lens-based practices can provide an immediacy of access to the experiences of others able to resonate within both gallery and clinical environments.

**Chapter 3: Membrane**, examines communication as fluid two-way exchange. The impact of the images of pain as an intervention in pain consultations with specialists from a variety of disciplines from homeopathy to surgery is analysed. Drawing on discourse theory as well as pain and visual theories this section identifies ways in which images disrupt normative verbal interactive patterns, to produce a richer vocabulary and more democratised dialogue. Quantitative and qualitative analyses are carried out on material from each strand of the project in order to understand the specific ways in which the images are functioning and their potential to encourage more negotiated and mutually beneficial dialogue. Specific contexts and ways in which the cards can be helpful are identified such as: eliciting discussion of the emotional components and impacts of pain and where the first language of clinician and patient is not the same. (This is primarily, though not confined to, chronic settings).

### **Complexities of pain and limitations of current medical framework**

Both Scarry (1985) and later Biro (2010) premise their work on pain's unsharability and incommunicability. One way of improving the efficacy and subtlety of communication I believe is through the use of images as an intervention capable of catalysing a democratisation and a tolerance of ambiguity within dialogue. Images act on our unconscious as well as our conscious minds allowing us to reflect on what has previously been less recognised, and feelings to surface and enter the room for discussion.

It is vital that these difficult and complex experiences of pain are voiced and witnessed in the consulting room and understanding of their multidimensionality increased in others. These experiences are not easy to fit within the existing reductive framework or measures into which the medical system tries to place them which serves to increase the isolation of sufferers. Isolation is claimed to

increase pain intensity (Eisenberger 2003). As evidenced by recent hospital scandals, such as the Staffordshire Hospitals (March 2013), a top down hierarchical communication system is still widespread within the medical community and medical training. It is not benefiting patient care nor creating a safe environment in which clinicians can develop. Professor Alan Bleakley has been at the forefront of the movement to bring the arts and humanities into medical training as part of its core curriculum (and thereby its insights into medical practice). He argues that the humanities can play a critical role *'in educating for democracy in medical culture generally, and in improving communication in medical students specifically'* (Marshall & Bleakley 2013 p 126). It is imperative we pay attention to the way communication happens within the healthcare environment, and particularly so in the management of chronic pain, exploring all avenues for improving it, including, and perhaps specifically, the arts and humanities. Pain is an area where reliance on communication for diagnosis occurs more than in almost any other area of medicine, and where sense of/destruction of self is intrinsically caught up within perception of the body and its sensations. The process of healing and re-building identity for chronic pain sufferers is more reliant on nuanced communication than on surgery.

### **Collapsing physical and emotional pain**

Physical and emotional processes intersect within pain experience. The language we evolve to communicate pain has to rid itself of a duality between physical and emotional pain, in a way such as Biro's redefinition of pain, quoted earlier, might permit (Biro 2012). Participants in the **face2face** project frequently report that they have been changed by 'pain', that their lives and identities have become fragmented. If this fragmentation, loss of the old and re-making of the new self is understood through purely psychological analysis then the body is marginalised. It is within the body that pain is re-making people and affecting the constructs of their subjectivity and inter-subjectivity. Note the title of Elaine Scarry's seminal book on pain. *'the making and the re-making of the world'* (1985). Academic Elizabeth Grosz (1994) provides a useful re-definition of subjectivity with which we can approach pain and the image. She theorizes the body as part of the construct of subjectivity rather than something affected by it. In a similar way, the photograph acts as both a physical object while signifying subjective experience. The image has been projected onto a surface, its

surface torn, etched or stitched into in a way which parallels the way narrative and experience are etched into our bodies. Can such a corporeal conception of subjectivity bring us closer to the lived experience of pain, removing the need for distinction between psychological and physical suffering?

Quoting Stockhausen in his programme notes to *Carre* (Square), composer Professor Jonty Harrison (2010) writes:

*Black and white are normally seen as opposites and, thus, mutually exclusive. However, says Stockhausen, by creating between them a scale of various shades of grey and then reordering the scale into a series, we effectively draw the apparent opposites of black and white into a higher unity – not black as the opposite of white, but black as a degree of white* (Stockhausen in Harrison 2010).

Could a visual language help create a similar scale for pain which allows shifts in perception necessary to accommodate both somatic and affective elements within one definition, framing them not as opposites but as degrees of each other?

## **Translation**

The **face2face** project and this thesis are not arguing for direct translation between medical and fine art language or knowledge. Academic Tim Matthews suggests that when translation is successful language in fact becomes less poetic. It follows that where translation is never quite possible a space is created into which we are invited to struggle with meaning. It is this type of space, initiating contact and negotiation between medicine and art, clinicians and patients, word and image that the **face2face** project seeks to create and the thesis to explore. It aims to be a space for exchange and transformation, expanding boundaries to accommodate new ways of communicating and knowing pain and illness.

## **The photograph that wasn't taken**

I would like to end with a photograph that was never taken, but which gave rise to all those within this project and thesis.

In 1999 I went on what for me became a hugely influential photographic student exchange with the renowned film and television school, FAMU in Prague, Czech Republic. I had already begun exploring the ways our lives and emotions do not fit easily into institutional social or architectural structures. As part of this research I photographed in: a hostel for the homeless, the Czech Houses of Parliament, Prague, and in two hospitals in Moravia where I visited babies on a neonatal ward and elderly patients on a geriatric ward. It was the last which gave rise to this work.

I went from room to room with a translator who asked the patients if they were happy to be photographed. Going into a room with an old priest in bed, with a cross above his head, the old man started crying. There was a moment where I wanted to take a photograph of his suffering. I resisted and put my camera down as the translator explained he wanted to talk to me but he couldn't speak. Later I was told in a tutorial with Czech photographer Jindrich Streit that this made me less of a photographer. '*Your job is to take photographs*'. I believe our job is to act with humanity towards each other.

The old man had had a stroke. We held hands, my camera lifeless on the cabinet. He couldn't speak; I couldn't image; the void between us was filled with pain and isolation, with no available language to cross it.

The photograph I didn't take remains more poignant than any I might have.

This is a journey to co-create a language with which to negotiate that space, and it is dedicated to the unnamed man who gave rise to this project and all those who seek to communicate their pain and suffering to others.

# MASK

*Under this mask, another mask. I will never be finished carrying all these faces.*  
(Claude Cahun, *Avenues non Avenues*, 1930).

*I am a man of many masks.* (Participating patient PD4, **face2face**).

It may be that to make a distinction between the face and the mask is a false dichotomy. The OED defines a mask as covering all or part of the face, a protective covering, but also references it as hiding ‘one’s *true character of feelings*’. What if the mask does not hide identity but is part of its construction - that it reveals identity? What if the body does not hide its secrets, to be uncovered by the technological or expert gaze of medicine, but through itself reveals them? What if maldynia, or chronic pain, does not require a muse but *is* the muse? In redefining maldynia, (chronic or *bad* pain), academic Giordano describes it as ‘...*pain without purpose .. multidimensional illness ... a durable event and experience of the lived body and life world.* (2011 p1). In their chapter on pain and art in the same publication, academics Cole and Carlin argue my own work might be ‘*understood as maldynia playing the muse*’, saying: ‘*Padfield’s art can aid in the communication process between the doctor and the patient, especially in the case of maldynia.*’ (2011, p 105). Of an image from the same body of work, **perceptions of pain**, (fig 3) academic Minae Inahara wrote:

*One half of a woman’s face appears as if she were using a theatre mask (akin to the one worn by the Phantom of the Opera) leaving one half of her face appearing as a smile and the other half showing pain and sadness. However, unlike the Phantom mask, this ‘mask’ does not obscure the face, we can see the lips, the eyes, and the skin, and this visibility highlights rather than hides her pain. It is not so much a mask as a magnifying glass, a magnifying glass that allows us to see her pain more vividly.* (Inahara 2012, p 190).

Inahara poetically identifies how the mask reveals as well as conceals. It is a hope that the images and narratives they elicit, from both projects described in this thesis, can reframe the mask of pain as a magnifying glass through which we see what it means to be human.



Fig. 1



# CHAPTER 1: THE MEDICAL PERSPECTIVE

## INTRODUCTION

*Pain crystallizes many fundamental truths about health, illness, and living. When a patient suffers chronic pain, having to dispose his or her life around its demands, the roots or at least the implications of physical symptoms become evident. "Where does the pain come from?" one has to ask when it does not go away. Not only what organ or tissue is responsible for the pain, but what, altogether, does the pain signify and call forth? What does it claim?*

(Charon 2005 p 29).

Pain is a slippery and subjective concept, its mysteries and complexities still not fully understood. It continues to evolve, as its meaning and significance change historically and culturally and medical knowledge increases. What doesn't change is the drive for those in pain to want to communicate it, to re-make something coherent out of the fragmentation of self it has effected, nor have the difficulties they encounter when trying to articulate and give form to their pain. The drive to communicate pain-experience, remains '*trans-national, trans-universal, trans-historical*' (Bourke 2011 b). This thesis, and the projects on which it draws, explore the possibility of developing a visual iconography for capturing pain which is '*trans-national, trans-universal and trans-historical*'.

### **Acute v Chronic or Maladaptive Pain**

Acute pain is essential, it signals danger and motivates action; painful stimuli nearly always signalling a threat to the integrity of the organism. A burn, a prick, infection or trauma creates lesions and signals danger, that something is wrong (Cabanac 2005 p 117). The common mis-conception that pain can be cured is probably due to significant advances in management of acute or post-operative pain, but raises unrealistic expectations for those with chronic pain. Although acute pain is useful for survival, for example it tells you to take your hand out of

the fire, or warns you there might be an infection;<sup>1</sup> chronic pain, in contrast, is defined as pain that has '*outlived its usefulness*' - a pain system which has '*gone wrong*'. Acute pain is usually caused by an obvious infection or injury and when treated or healed, it goes away. When pain lasts more than three months, it is described as chronic or maladaptive and the original cause can often no longer be identified. Chronic pain can occur even after healing and be present with or without a lesion. Due to alterations in the nervous system, pain can occur when no tissue damage is detected (central sensitization Woolf 2007 cited Bradbury 2011). Pain signals to and from the brain have not 'switched off' and the brain has developed a memory for transmitting pain. Chronic pain is therefore no longer a warning signal, but a faulty signal which can arise in any structure of the body. Professor of Clinical Medicine, Columbia University (and originator of the term 'narrative medicine'<sup>2</sup>) Rita Charon, describes this '*unrelenting or pointless pain*' – as betraying the person '*who lives in that hurting body, thwarting the usual happy mindless comfort one expects from one's body, refusing to be placated by anything less than a full accounting of 'ones relation to one's body*' (Charon 2005 p 29). It reminds us of the deep integration of mind and body; pain though experienced via the body is processed in the brain. Psychiatrist Andrew Hodgkiss makes an interesting point that it is the patient who makes a decision that he or she is ill. However it is the clinician who makes judgments on the presence or absence of a lesion, and thus on the perceived legitimacy of pain (Hodgkiss 2000 p1). That distress can affect immunological responses, or affect the way pain is processed is not the same as saying a person has *poor coping skills* or the pain has a *psychological root cause* which so many pain patients spend an inordinate amount of effort trying to refute, often leading to behaviours which exacerbate pain and its impact on life. Pain specialist and ex-medical director of Input Pain Management Unit, St Thomas' Hospital, London, Charles Pither asks:

*What if the doctor can find nothing wrong, but the pain gets worse? The doctor, believing more in the 'hard facts' obtained from investigations, undermines the patient's subjective account, and implies that the problem is not as bad as the person makes out, or that emotional problems are to be blamed. In essence the patient's proposition of illness has been rejected. (Pither in Padfield 2003, p 125).*

Many now argue for chronic pain itself to be classified as a 'disease' in its own right. Professors Cole & Carlin in their chapter on chronic pain (2011) cite neuroscientist James Giordano as suggesting that '*Maldynia*'<sup>1b</sup> (unremitting chronic pain and subjective suffering) is emerging in the postmodern era because of the ability of medical technology to extend the life span (Giordano 2011). However, techno-centric medicine, they argue, is ill-prepared to address the bio-psycho, social and cultural consequences of such an epidemiological transition from acute to chronic disease.

### **Visibility/Invisibility and the doubt of others**

In her book *The Transparent Body* (2005), academic and Professor of Media and Culture, University of Amsterdam, Jose van Dijck argues that although '*Medical imaging technologies have rendered the body seemingly transparent; we tend to focus on what the machines allow us to see, and forget about their less-visible implications*' (van Dijck, 2005). There are numerous aspects to the pain experience which might fall into this category. Van Dijck questions whether despite a host of technical tools used to visualize the interior of the body, it has '*as a result, become more transparent*' at all?' This is apposite in relation to pain, particularly chronic pain. We can see pain nerve cells down a microscope (Price et al. 2003). Researchers can describe the changes taking place in the emotional and cognitive centres of the brain, which modify the experience of pain using recent developments in functional magnetic resonance imaging (fMRI's ) (Wiech et al. 2008). However there are as yet no successful medical imaging tools for visualising the subjective experience of pain. The most obvious consequence for patients is well documented; they feel, and often are, disbelieved (McMahon 2006, Brown et al. 2008, Padfield 2003). Paradoxically in an age where we increasingly rely on technology to make the body transparent and thus legible, we have become less tolerant of that which is opaque and invisible; less able to 'read' aspects of illness, pain and disease which cannot be accessed by technology, abandoning such experiences to spaces of illegibility, ambiguity and contention. Precisely because of their tolerance of ambiguity and polysemy, visual images, in particular photographic images, can complement the multidisciplinary approaches already used by most pain management teams.

Chronic pain frequently has no visible lesions evident through current medical

imaging techniques, such as MRI's or X-rays, leading to frustration for patients. If it is not visible, is it 'real'? The pain experienced is always 'real', but many patients suffer from the doubt of others. Addressing the disbelief of others and validating the suffering of those in pain, is a central theme running through both **perceptions of pain** and **face2face**.

In her seminal treatise on pain, academic Elaine Scarry writes: '*To have great pain is to have certainty, to hear that another person has pain is to have doubt*', (Scarry 1985). This is echoed by myriads of patients I have talked with:

*You can't see pain so people don't believe it. I had that even more so with doctors. They would say "you don't look like you are in pain" and many of them did not believe me. I could be crawling round the floor but it would not help. One doctor sat there and said "You cannot be in the pain you say you are in." I said, "What do you want me to do to show you I am in pain?" (participating patient **perceptions of pain**).*

The doubt of others exacerbates the suffering of those for whom it is the most certain experience they have, increasing their isolation (Melzack & Wall 2006).

### **What is pain?**

We might ask therefore, if we cannot image it, we cannot tangibly identify it, what is pain like this, pain without a function? Can we agree on what it is, what significance it holds for us? Modern concepts of pain have moved from an elusive simplicity of a pathophysiologic lesion that represents the 'seat' of a pain, towards a complex neural and cortical process now thought to 'explain' pain, including its cognitive and affective elements. (Padfield et al. 2010 p144). That is, pain is no longer seen as a 'spot' of disease, to be excised or healed by an expert, but as a set of systems interacting with the self to produce the experience of pain, requiring perhaps understanding by an interpreter more than an offering of cessation of suffering by an expert? There is, therefore, unlikely to be a quick fix or a cure for chronic pain sufferers. However, patients understanding the significance and meaning their pain holds for them, how it intersects with their life and physiology, a sense of control over how that experience is understood and 'narrated' by and to others, can reduce its intensity. Despite this being generally acknowledged by those who treat pain,

according to Prof Joanna Zakrzewska 25% of patients (understandably) continue to identify their main treatment goal as “*to be pain free*”. (Napenas et al 2011). ‘*There is still ‘little public recognition that chronic pain cannot be cured, although it can be managed*’<sup>3</sup> (Zakrzewska in ***facing pain***, Padfield 2011). Through involving patients in the co-creation of images reflecting qualities of their pain, can they regain more control over that experience, how it is constructed and perceived by others, and so participate more equally in their own healing? GP and pain specialist in the community, Dr Francis Cole (2005), writes about the importance of patients taking control in order to overcome chronic pain. Francine Ozarovsky echoes this in the film ***duet for pain*** (Padfield 2012): ‘*That I am not at all in control of the pain in my neck, is totally a disaster ... when you feel in control, you always feel a little bit better*’.

### **Chronic pain and its position at the margins of medical practice and communicability**

Psychiatrist Andrew Hodgkiss describes chronic pain, or pain without lesion, as lying ‘*at the limit*’ of medical knowledge and practice, revealing ‘*the limitations of the clinical method we still employ*’ (Hodgkiss 2000, p3). I would suggest that like many phenomena inhabiting the margins of experience, it can help us understand ourselves better.<sup>4</sup> Lying at the margins of clinical practice, even perhaps the margins of language, it is better placed than any other area of medicine to help us engage with the extremes of human emotion and sensation, how they inter-relate and how they relate to contemporary medical practice.

It reveals conversely our difficulties in accepting our own limitations, of tolerating ambiguity, accepting the unknown, perhaps even our own ‘human condition’, of which pain could be seen as an integral part. The medical anthropologist Arthur Kleinman views care-giving as an essential part of being human. The corollary is accepting the suffering which calls for care-giving as also part of the human condition, calling for and teaching us empathy:

*... For the medical humanities and interpretive social sciences, care-giving is a foundational component of moral experience. By this I mean that care-giving is envisioned as an existential quality of what it is to be a human being. (Kleinman 2008 p23).*

Rita Charon sees pain as exposing some of the fundamental truths about medicine: *'Issues that in other fields of health care might be treated as marginal or fleeting are, in pain medicine, irrevocably central: trust and trustworthiness, steadiness of commitment, investment in the patient's future, and recognition of the other'* (Charon 2005 p 29). It is an awareness of the others' perspective that is challenging to many medical consultations, but particularly so to pain consultations. Pain, more than almost any other area of medicine, makes demands on language inextricably bound up with the demands of moving beyond our individual experience to empathise with that of another (Padfield 2003 p 17).

### **Illness narratives as stories**

One way of accessing the experiences of others is through stories. Charon believes that sickness itself unfolds in stories (2000 p 31), advocating narrative competence as an essential skill for pain clinicians. She identifies how, for example, a head pain comes into existence as a story told in *'acts of narration'* unfurled through the unusual bodily sensation being put into words, told and re-told by the sufferer. The sensation accrues language, and once *'specific language is associated with the symptom (it is called sinusitis or migraine or subdural hematoma), specific action occurs that is tailored to make it go away.'* (ibid p 31). Literary Scholar Steven Marcus (1975 p 277) goes so far as to suggest that *'Not only might one understand the meaning of symptoms through telling and listening: the telling may in fact cure the illness.'* (Cited in Charon 2005 p 32). The images produced during the **face2face** project are designed as triggers for eliciting narrative. Narrative approaches to medicine will be discussed later in this chapter (page 58), but critical to this is Charon's claim that *'one of the central aspects of pain medicine that is undetectably central to all of medicine is narrative.'* She explains: *'simply speaking, a narrative is a story that has a teller, a listener, a language, characters, a plot and time'* (ibid p 29), ie that there is listener and a teller. It is the relationship between listener and teller, the interplay of roles that to some extent this thesis attempts to unravel. What is worth observing is that usually the 'teller' knows the end of the story. In a medical consultation, however, the end of the story is in the process of being constructed, so the teller's part in that construction or co-construction is pivotal. During effective communication, I feel these roles pass from one to the other fluidly and do not get fixed in one position. In contrast, many of the images co-

created during **perceptions of pain** and **face2face** reflect a lack of movement, (see figs 4,5 and 6). In many pain consultations instead of fluidity there is stasis with patients and clinicians vying for the role of speaker. Sociologist Diane Kenny gives examples from her study of doctor-patient communication where patient and doctor both expect *'to function as speakers, not listeners, with the consequence that neither doctor nor patient felt heard by the other'* (Kenny 2004 p 303). Medical educationalists Marshall and Bleakley describe how medical students at Peninsula College of Medicine and Dentistry (UK) are *'encouraged not to 'take' a history, but to 'receive' it'* (2013 p1), a subtle but interesting distinction advocating active listening. Greenhaigh and Hurwitz, who claim that both those seeking medical help and those providing it accept the narrative nature of medicine, stress that the listener must be caught up in the story and must appear to be listening (Greenhaigh and Hurwitz 1999). As Elaine Scarry so famously asserted however, pain resists language (Scarry 1985). This creates a problem for those experiencing or treating pain, however much they may accept the role of narrative in medical care. We do not have an effective language with which to communicate the experience of pain to others, and to some extent we cannot even agree on what 'it' is we wish to communicate.

This thesis hypothesises that a collection of photographic images of pain, developed during the **face2face** study at UCLH, can be a new tool for eliciting narrative, facilitating effective two-way exchange and communication of chronic pain.

### **Pain and/or Suffering**

*Yet, I do believe that what doctors need to be helped to master is the art of acknowledging and affirming the patient as a suffering human being; imagining alternative contexts and practices for responding to calamity; and conversing with and supporting patients in desperate situations where the emphasis is on what really matters to the patient and his or her intimates* (Kleinman 2008 p 23).

Kleinman identifies not only the need for effective communication but the level of suffering attached to pain. There is a debate, I consider relatively semantic, in relation to chronic pain, about whether there is a distinction between pain and suffering. Professor of Neurosurgery John Loeser (USA) questions whether

suffering is an inevitable intrinsic part of or a consequential 'add-on' to pain:

*Suffering is a negative affective response generated in the brain by pain, fear, anxiety, stress, loss of loved objects, and other psychological states. What we do not know is whether this negative affective response to pain originates with the brain when information saying "pain" is received, or whether nociceptive information reaching the dorsal horn leads to the activation of circuits leading to the production of both pain and suffering at the spinal and brainstem levels. That is, is suffering added onto pain in the brain? (Loeser 2005 p19).*

The problem with attempts to define pain separately from suffering is the separation of mind from body it pre-supposes. Eric Cassell, (1982 cited in Cole & Carlin 2011) appears to support such a distinction by arguing that medicine, while focusing on pain and bodies, has not focused enough on suffering, suggesting that "*Bodies feel pain*", while "*people suffer*". Current research is increasingly demonstrating the integration of mind and body within pain processes and arguments for there being a relationship, but distinction, between pain and suffering appear to undermine this. I believe that where pain is chronic, there is always suffering. According to Chapman and Nakamura (1999) both pain and suffering require consciousness. Loeser expands this posing the dilemma that reflex responses to noxious stimuli can occur without consciousness, although he counters this by citing neurosurgeon Livingston's (supervisor to Ronald Melzack) pioneering work on chronic pain who was convinced of the plasticity of pain mechanisms, claiming: '*Nothing can properly be called 'pain' unless it is perceived as such*' (1998). The aim of this thesis is not to do justice to an exploration of the inter-relationship between pain and suffering, but in accepting them as inevitable parts of one another to understand them better. Loeser's chapter on '*pain suffering and the brain*' (2005) provides a full discussion of this topic, concluding that as '*The brain is the organ of behaviour; the only sure cure for pain or suffering is decapitation*' (Loeser 2005 p 17). To my mind this answers his original question, that in relation to chronic pain anyway, suffering is an intrinsic part of pain. Rita Charon collapses suffering and pain into one sentence, as many do when they speak of '*pain sufferers*'. Of pain patients she writes: '*A scientifically competent medicine alone cannot help a patient grapple with the loss of health or find meaning in suffering*' (Charon 2001a).



This returns us to American Academic and physician David Biro's advocacy of an expanded definition of pain (see page 22) making no distinction between physiological and psychological suffering. It is to the meaning of pain and suffering that we return and will return time and again throughout this thesis. The challenge, as sociologist Diane Kenny has pointed out, is not to make a schism or conflict between the psychological and the physiological, but to recognize that they are inextricably intertwined in most chronic contexts. *'The challenge for Western Medicine is to search for potentially healing interactions between doctors and their patients that do not rely on the biogenic model of the visible body or the psychogenic model of invisible pain'* (Kenny 2004 pp 297 - 305). She describes the way in which Sociogenic theory demonstrates how *'medical failure to legitimate (non-organic) pain leads to alienation, depression, anxiety, and renewed efforts at legitimation. This process sets up a chronic pain cycle that Williams (Williams 1993) described as both '... a fountain of hope and a font of despair'* (Kenny 2003 p 129). If we accept suffering as an inevitable part of chronic pain, then the question of finding a language with which to communicate and understand it becomes ever more pertinent.

This thesis hypothesises that using photographic images within medicine might be one way of facilitating an integration *'between physiological, psychological and social meanings'* such as argued for by medical anthropologist, Arthur Kleinman (1988 & 2008 pp 22-23). It discusses the limitations of current medical measures for pain necessitating such a tool. It explores the potential of metaphoric and aesthetic spaces to expand dialogue beyond what is normally available within the consulting room, and finally analyses how these pain images appear to be functioning to facilitate integration of discussion of affective elements of pain-experience into mainstream medical dialogue. It demonstrates how the pain cards produced during the project can give a tangible and sharable form to something as slippery, intangible and invisible as pain, impacting positively on patient-clinician communication, and arguing effective balanced communication is an essential, rather than a desirable, part of pain management.

It contributes to current expansions in pain management research and original evidence on the value of arts practices to the growing field of medical humanities. In his introduction to his publication exploring the benefit of multidisciplinary perspectives on chronic pain, (one chapter of which analyses

the ***perceptions of pain*** project), neuro-scientist and neuro-philosopher James Giordano (USA) writes:

*Exploring how a contemporary science of pain impacts and is affected by the humanities may help to refine our current knowledge of the brain, mind, self, and society, and may help to chart a course forward in pain care. (Giordano 2011 p 4).*

Kleinman (1988, 2008) and Giordano (2011) argue for a humanistic approach to medicine. This is supported by Kenny's descriptions of the ways in which the search for legitimisation by many chronic pain patients leads to cycles of endless investigations and pain behaviours often resulting in alienation and stigmatisation (Kenny 2003). Rather than distinguishing between appropriate or inappropriate levels of pain, which tends to block any successful partnership between care provider and patient, Kleinman, Kenny, Charon, Zakrzewska and others recognise the importance of narrative to pain and healing and the relevance of the social and cultural context in which pain takes place (see also Bass 2002). Methods which recognise the relationship of these to pain experience, such as the use of visual images as triggers to dialogue, might help us move towards an approach to pain management and to consulting more appropriate for the 21<sup>st</sup> century and the rise of chronic illness.

## **CHANGING THEORIES AND CONCEPTUALISATIONS OF PAIN**

Conceptions and visualisations of pain not only differ from person to person, but between historical periods. Historian, Professor Joanna Bourke argues our conception of pain affects our physiological as well as emotional experience of it (Bourke, 2011 a and 2011 b). There is no absolute fixed definition of pain. In '*Pain and the Politics of Sympathy, Historical Reflections, 1760's to 1960's*', Professor Bourke describes how the body feels pain differently when it forms part of a different system of meaning (Bourke 2011a).

In a recent personal interview she expanded saying:

*What is interesting is showing how foreign the past is, how unusual. Physiology is not universal, it has changed over time, so if you have a*

*completely different understanding of the body you will feel it differently, the meaning given to pain is vastly different in earlier periods. The way the body responds to pain alters because of these different systems of meaning (Bourke 2011 b).*

Her argument highlights the need to understand the schema and systems of meaning into which patients are placing their pain in order to treat them. This cannot be done except by making effective two-way communication central to the consultation. Discovering the schema into which a person fits his or her pain, does not distract from a medical focus<sup>5</sup> - it needs to be seen as an integral part of that focus, discussed in a way which can allow sufferers control over their pain through better understanding, facilitating clinicians to treat and refer appropriately.<sup>6</sup>

### **A brief history of pain**

Within the ancient cultures disease and pain were seen as divine punishment for collective transgression, the natural world perceived as divine, and pain an expression of that divinity. For the Greeks, pain and disease could be deserved through personal fault, collective fault or even according to Sontag, ancestral crime (Sontag 1977 p43). Unlike the ancient world where pain and disease were conceived as divine punishment, the word pain, deriving from the Latin 'poena', meaning punishment and penalty, Hippocrates (460 – 370 BC) believed that pain was not part of a divine schema, but related causally to disorder and disease, making it a normal part of life, a natural phenomenon. Illness was conceived as a process and pain the direct result or evidence of specific disease. Medical historian, Valadas describes how the Hippocratic approach supported a '*valorization*' of the relationship between physician and patient, emphasising interpersonal engagement between physician and patient, as a way of gaining access to the subjective and invisible elements of illness and pain (Valadas 2011 p 9). He argues that pain was not seen as having any positive value itself and health constructed as a lack of pain and suffering (ibid 2011 p9). A few centuries later, Galen (AD 129-200) framed pain as a warning sign, part of a system of protection. He accepted Hippocrates' system of four bodily humours: blood, yellow bile, black bile, and phlegm, identifying them with the four classical elements and the seasons. Based upon Platonic theory, he posited that '*there were three bodily systems, heat, liver, and brain – and*

*contested the Aristotelian idea that the mind was in the heart, claiming instead that it was situated in the brain'* (Valdas 2011 p 10). What I find interesting in his theories in relation to contemporary studies of pain mechanisms is that his experiments established that the brain had what he perceived as a dual nature, *'simultaneously "soft" (so as to harbour functions of imagination and intelligence) and hard (to serve motor and bodily functions)'* (Valdas 2011 p10). How far away is this from functional imaging studies into the effect emotions have on modulating the experience of pain? (Wiech et al. 2008). At the same time neuroscientist Prof. Irene Tracey and her team are studying neural activity at the micro level whilst evidencing the role that cognition and emotion play in the processing of pain – is this another way of integrating research into what might be perceived of as “hard” and “soft” systems within the brain?

In the seventeenth century with Wiliam Harvey's research, and the discovery of the circulation of the blood and conception of the body as designed to *'execute particular functions'*, came the emergence of medicine as a science (Valdas 2011 p 14). In his summary of the history of pain Valdas concludes that the consequent causal understanding of the body played a significant role in conceptualizing the mind-body relationship and concomitant view of pain (ibid p 14).

Descartes (1596-1650) correlated pain with *'perceptions of the soul'*, famously asserting the duality of mind and body, or soul and body (ibid p 14). It has taken centuries to undo this Cartesian split and to re-integrate the body and brain into one complex, inter-relating and plastic pain perceiving mechanism. The intertwining of body and cognitive processes within the pain experience has not always been seen as only taking place within the individual (Bourke 2011 a). With the discovery in the 1760's of the sympathetic nervous system, came a conception that one person's nerves and another's were physically interconnected so that, in Bourke's words:

*when you stub your toe, not only does the sympathetic nervous system work within yourself, you feel nauseous you have a headache, but I, me, looking at you affects me, I get nauseous, I get a headache. So your body and my body are interrelated, interconnected, it is completely physical* (Bourke J. 2011 b).

This might have come full circle to science's current interest in mirror neurons. Mirror Neuron theory is the firing of neurons thought to contribute to our ability to read another's face, to empathise with another's experience, so that when we perceive pain being inflicted on another, parallel neurons are fired within our own system, so that we almost 'feel' another's pain (Rizzolatti & Sinigaglia 2008). By the end of the eighteenth century, the concept of 'sympathy' constructed pain as travelling from an injured part to different parts of the body (Valdas 2011 p 18). Both Valdas (ibid p 18) and Rey (1993) (cited in Hodgkiss 2000, p 29), describe the notion of sympathy as: *'a bridging-theory, between humoral theory and the neuroscience of the nineteenth century, paving a path for physiological observations which would lead later to the scientific analysis of the neurological system'* (Valdas 2011 p 18).

In the 'scientific' age of the nineteenth century, anaesthetics, and the debate about the value or use of anaesthetic emerged. Pain could now be avoided through chemical processes. But can it and has it? It paved the way for the anaesthetists of the twentieth century to become the pain specialists of the future in the newly forming sub-speciality of pain medicine. As someone whose *raison d'être* has been to make pain tangible, visible and more conscious, I find it an intriguing development that those charged with treating pain have become those expert in anaesthetising it, rendering it invisible, less tangible, and relegated away from conscious control and back within the unconscious! It is interesting that this movement towards anaesthetising pain was taking place at roughly the same time as Charcot and Freud were developing their 'talking' therapies – highlighting the role of the unconscious within suffering and the consequent possibility of a somatisation of pain. Freud's methods were based on therapeutic listening to what the patient said (Freud 1955). Charon describes his methodology of psychoanalysis as the *'evenly hovering attention of the analyst'* convinced that there is *'truth to be heard about the patient's illness by listening to their words'* (Charon 2005 p 32). It is the very opposite of rendering the patient unconscious. There is however a recent trend away from pain specialism as the preserve of anaesthetists and a shift towards a more integrated mind-body approach as advocated by doctors such as rehabilitation expert and researcher Hillel Finestone, M.D. Finestone's self professed *'holy grail'* is to act as a *'pain detective'* (the title of his recent book, Finestone 2009), to retrieve and reveal the key psychological and sociological components within an individual's pain experience in order to *'figure out their pain'* (Finestone 2009).

pp xiv-xv). His is not a typical anaesthetists approach. Claiming that, despite the *'billions of dollars per year expended on pain treatments, primarily physical pharmaceutical related, not enough is spent on understanding those who are experiencing the pain, the circumstances under which they live, their backgrounds, their stresses and their actual lives'* (ibid p1). He argues that although *'many psychologists and sociologists study pain, and many excellent research projects have resulted from their work, integration of their findings into mainstream medicine is lacking'* (ibid pp 4, 5). He cites various studies equating stress with delayed ability to recover from wounds and a deleterious effect on skeletal muscle. The tide may at last be turning away from a focus on anaesthetising pain and moving towards a more integrated psychosocial approach towards its management.

Whereas in the 18<sup>th</sup> and early 19<sup>th</sup> centuries doctors were dependent on language and narrative these increasingly became replaced by clinical tests, the invention of the stethoscope, and a huge array of scanning machines so that the doctor no longer felt he/she needed to listen to the patient's story to diagnose. The doctor became more distanced from the patient's narrative and his/her gaze became mediated via machinery. *'It's almost viewed as counterproductive to listen to the patient story, because it distracts them from the "real" problem which can be done through a chemical test and so inevitably listening to patient narrative moves down the medical hierarchy, moving from doctors and physicians, to top nurses and then to the aids and the cleaners.'* (Bourke 2011 b).

Psychiatrist Andrew Hodgkiss asserts that Foucault's introduction of the term 'medical gaze' shifted reliance on the patient's words to examination of his body. Hodgkiss also asserts that Foucault goes onto argue that a transformation in the power relations between doctor and patients was then at stake. (For a full discussion of the different kinds of power Foucault associated with the doctor-patient relationship, such as a distinction between the capillary power identified as belonging to the patient and the doctor's exercise of 'sovereign power', please see Bleakley (2011). From being servants of the eighteenth-century French gentility, physicians in public hospitals began to see large groups of poor patients as research fodder and they offered their bodies as objects for the medical gaze at the cost of respect for their subjectivity (Hodgkiss 2000 p2).

During the nineteenth and twentieth centuries the science of pain medicine developed rapidly. I am taking a great leap to jump to Melzack and Wall's development in 1965 of the 'gate' theory of pain as it marked a watershed in pain research. It is a major landmark laying the path for current pain research.

Melzack and Wall proposed the 'gate control' theory, which described pain as a system of neural circuits from the periphery to the brain which *interacted with each other* (Melzack and Wall 1965). The system was seen as *plastic* with 'gates' within the system which could suppress noxious impulses. This 'Gate Control Theory of Pain' though not completely accurate, after fifty years still serves '*as the template for almost all subsequent depictions of the pain and analgesic system*' (Valadas 2011 p 23) It is the basis of the current biopsychosocial model of pain (Bradbury 2011).

What was new about Melzack and Wall's theory, and relevant to this thesis, was the concept that messages signalling pain were *modified* by the brain, that pain was the result of a series of systems interacting with and modifying each other and not one mechanism, ie it was an evolving and plastic system. The system receiving pain messages is itself modulating those messages. Much current research focuses on the plasticity of the brain and its intersection with pain processing systems.<sup>10</sup>

This indicates that our emotional responses to pain directly affect how our pain is processed and thus the level of pain we feel. Understanding and revealing these emotional impulses and the narrative they emerge from can help modify the pain intensifying process, as neuroscientist Prof. Irene Tracey and her research team in Oxford are demonstrating (Wiech et al. 2009, Tracey 2007). Melzack and Wall's work has led to detailed current research at a basic science level, where although pain itself defies imaging, pain neurons and pain activation systems have become visible. Maybe one day all this complexity will be reduced to a simple understandable process, in the way Sontag believed a singular understanding of cancer might evolve to strip it of its mystery. For now, pain processes appear highly complex, and despite all attempts to define and understand it, the internal subjective experience of pain eludes medical visualisation.

While subjectivity has not yet been visualised, its role in pain experience is commonly acknowledged, which returns us to the relevance of the **face2face** work. With their relationship to perceived authenticity and ability to document 'reality', photographic images co-created with pain sufferers are an apposite medium for making the subjective visible, documenting the subjective reality of another and conferring authenticity on it. They are a means of imaging pain.

### **Contemporary medical pain theories**

Although 'pain' itself is still not visible there are a host of pain researchers able to 'see' pain neurons, researching at a micro-level how and why chronic neuropathic pain signalling is maintained. Neuroscientist, Prof. Maria Fitzgerald's (UCL) work for example is beginning to demonstrate how the neural system is formed during infancy and how it interacts with other systems to produce and maintain 'maladaptive' pain. By deduction it is clear how significant early experiences of pain are. I would argue these early experiences not only affect our perception of pain at a neuronal but at an emotional level, refer for example to the IASP definition of pain claiming each individual '*learns the application of the word through experiences relating to injury in early life*' (page 21). Fitzgerald investigates the long term consequences of early life pain and injury on adult somatosensory and pain processing (Fitzgerald 2004a, 2005, 2006). Although at a neural level, her research inevitably intersects with patients' emotional and physiological histories, evidencing the impact that early traumatic events have on the development of the pain processing system, and thus experience of pain later in life (Simons et al. 2003, Stevens et al. 2000, Anand 2000, Fitzgerald and Walker 2003, Fitzgerald 2004 b). The neurobiology here could be said to be supporting the discoveries of narrative medicine, and vice versa. There are many laboratories exploring the way that physiological systems are interacting with cognitive and emotional processing systems, (Morley 2008). It seems the more we learn about pain processing, the more complex and intriguing it becomes.

There are countless papers describing a neurobiological basis for the interaction of psychological and physical components within pain, advocating that greater knowledge in this area could '*enhance therapeutic outcome*' (Gundel and Tolle 2005 p 89). Gundel and Tolle cite a recent neuro-imaging study examining the



neural correlates of social exclusion pain and physical pain hypothesising that the same brain regions are activated (Eisenberger et al. 2003). Eisenberger examined the links between hurt felt as a result of ‘*social rejection*’ and that felt as a result of physical damage: ‘*Activity in the dorsal ACC [anterior cingulate cortex], previously linked to the experience of pain distress was also associated with increased distress after social exclusion*’ (Eisenberger et al. 2003, cited in Gundel and Tolle 2005 p 106). He and his team famously claim their results provide further evidence that the experience and regulation of social and physical pain may share a common neuro-anatomical basis. This parallels Prof. Irene Tracey’s work on emotional processing, Tracey herself asserting that Eisenberger’s results suggest ‘*social pain is analogous to physical pain in its neurocognitive function, perhaps alerting us when we have sustained an injury to our social connections and explaining why it “hurts” to be insulted or why we feel such “pain” when we lose someone we love.*’ (Tracey 2005, p 147). If social exclusion is evidenced as an intensifier of pain, then any tool, such as the images which can expose and reduce such isolation, becomes medically relevant.<sup>7</sup>

The work of Prof. Tracey and her laboratory in Oxford investigates the neural mechanisms of pain perception by using advanced functional imaging of the brain.<sup>8</sup> They evidence how anticipation and anxiety can affect and exacerbate pain perception (Lanetti et al. 2005). Tracey’s research explores mechanisms related to plasticity and inflammation within chronic pain states investigating the different regions activated during pain processing. Her work is pivotal in demonstrating the effect emotions and memory have in modulating how pain is felt. Using recent developments in fMRI’s she and her team can now describe the changes taking place in the emotional centres of the brain during pain processing, which literally change its perception (Wiech et al. 2008). The question is, how can these be harnessed to put patients more in control of their pain experience? Addressing this, her team have been researching the possibility of using fMRI’s to produce ‘*readouts*’ of the pain experience. These are images of the brain which support the likelihood of the pain having either a mechanical or psychosocial cause, indicating different treatment routes, ie pharmacological/ surgical interventions or cognitive behavioural therapies (Tracey 2005 p 137). Tracey argues that the fMRI images, although not an ‘*image of pain*’ are ‘*nevertheless a reliable marker for the subjective pain experience*’ and that identifying through the fMRI’s ‘*where the pain is coming*

*from ... will better guide us to the location or primary contributing factor.'* (Tracey 2005 p 147). She references other fMRI studies supporting her thesis, for example Coghill et al. (2003) and Eisenberger (2003). Coghill uses fMRI to assess links between pain reporting and the evidence for increased sensitivity to pain as shown in brain imaging, concluding *"that highly "sensitive" individuals exhibited more frequent and more robust pain-induced activation of the primary somatosensory cortex, anterior cingulate cortex, and prefrontal cortex than did less "sensitive" individuals."* (cited in Tracey 2005 p 138)

The research is extremely exciting and of great value in helping unlock some of the mysteries of pain, but I would be cautious of using fMRI 'readouts' to determine how much psychosocial or emotional causes are contributing to an individual's pain. I believe there is something problematic about using a mechanically generated image whereby a patient is completely objectified to 'reveal' something as subjective as the emotional or psychosocial component of individual pain. I imagine many patients might take issue with this, and that although the research has been vital in providing evidence (mostly I think using healthy subjects) of the intersection of emotional processing with pain processing there are problems with using this type of 'readout' as a measure of pain on a regular basis with NHS patients. Tracey, correctly I think, asserts that the lack of objective measures to "rate" pain contributes to a culture of disbelief in patients' narratives. However I am unconvinced that attempts to objectify or validate pain reporting through fMRI imaging will rectify this, in fact relying on a mechanized gaze to legitimate personal narrative could compound the effect of de-personalisation and isolate patients further. Conversely, I believe using the pain cards to elicit significant narrative is less invasive, less objectifying and a less contentious way of revealing much the same information at significantly less cost. Using the cards as triggers, rather than hard diagnostic measures, I believe would encourage a collaborative relationship between patient and clinician in the construction and understanding of pain narrative in its social context. It would allow patients to reveal only as much as they want or need to, involving both care receiver and provider in the process of unpacking and assessing its relationship to the continuation of pain, rather than on a mechanized means of 'legitimising' or not, the cause of their suffering. The cards aim to promote discussion of those elements which can so often remain hidden, embarrassed, forgotten, feared, felt to be insignificant or non medical, while maintaining the patients agency within the process of 'revelation'. The choice

of cards may not only differ from person to person, but vary from day to day for each individual. In this way difficult aspects of experience can be brought into the heart of medical discourse for clinician and patient to discuss together discovering their impact on pain.

### **Contemporary medical pain representations, measures and their limitations**

#### **Rate your pain on a scale of 1 – 10**

Most current medical pain measures commonly used are verbal or numerical, such as the verbal rating scale (VRS), visual analogue scales (VAS), Brief Pain Inventory or the McGill Pain Questionnaire (MPQ). These can fail to capture an experience as multifaceted as pain. For example, one of the pain sufferers I worked with during my original project *perceptions of pain* (Padfield, 2003 p 53) declared: *Pain = evil; evil = darkness; darkness = pain.*

This sentiment demonstrates how futile it can be to ask patients to constrict their experience into a number on a scale from 1 – 10? The phrase above reflects the isolation and hopelessness of an intense and multifaceted experience unlikely to be conveyed by a number; it also reflects notions of pain enmeshed within those of punishment, retribution, even criminality, with religious or mythical undertones . (see page 82 on pain and metaphor). The rating scale is problematic, additional to its limited ability to capture the complexity and intensity of emotion demonstrated above. The reason a certain number is offered often says more about the social context in which a person is being asked, the number they feel 'appropriate', the role they are 'performing', the use or function a particular number might be put to, than it does the intensity of their pain. Numbers selected vary between individuals and even within the same individual between different emotional states.

The Pain Inventory or McGill short form questionnaire, the most widely used measure currently, has similar limitations. Its strength is perhaps its assumption that it is important to assess not only the *intensity* of patients' pain, but also its *quality* (Semino, 2012).

*It is now evident that the word 'pain' refers to an endless variety of qualities that are categorized under a single linguistic label, not to a specific, single sensation that varies only in intensity. Each pain has unique qualities. (Melzack 1975 p 278 cited Semino 2012).*

The McGill Pain Questionnaire (MPQ) asks patients to constrict their experience into pre-existing formulae, here a series of words. The McGill offers a list of 78 different adjectives in groupings describing different qualities, eg those associated with temperature or with affective aspects, for example, subdivided in relation to intensity. Patients are asked to select words only from groups which reflect their particular pain quality/intensity. It has the advantage of spontaneity in that it is often done with clinicians in a quick run through the words and that way may highlight the most troublesome quality of the pain quite quickly. Its development involved input from pain sufferers, we are told, and so should have authenticity, but there are limitations to the process. Firstly it forces patients to describe their pain using adjectives, adjectives not arising out of their own worlds, but pre-prescribed words. Secondly although the words they can choose from have indeed been gathered from real pain patients, they are patients from a distinct community with a distinct vocabulary not necessarily reflecting the language the majority of patients might actually use, eg 'lacerating' and 'lancenating'.<sup>9</sup> There are occasions where the words can be useful in identifying certain types of pain, for example the "*burning*" or "*tingling*" of neuropathic pain, (these words are also found in other pain screening questionnaires such as Pain Detect (Bennett 2007), the "*shooting*" of TN pain and the "*aching*" of muscle pain. However it could be construed as yet another reductive system whereby people have to fit their experience into the shapes and sounds of others, and are subsequently left with a choice, - do they comply hoping it might elicit help from their clinician believing that if they 'do it well enough' a diagnosis might emerge, or do they resist, and if they resist what are the consequences for their medical care— will they be labelled difficult, will they encounter barriers accessing treatment? Melzack and his team claim that: *'patients are grateful to be provided with words to describe their pain; these kinds of words are used infrequently, and the word lists save the patient from having to grope for words to communicate with the physician'* (Melzack 1975 p 283).

I think the process denies patients the opportunity to create their own metaphors and expand their pain descriptions using language drawn from their own social

worlds. It is in the struggle to find apposite words, to create new descriptors, to ascertain whether the other has understood or not, that more unusual and individually significant words can emerge. Although many clinicians feel that using a standardised system in very large numbers can be useful because it has been tested and thus validated, I believe that having ready-made words can limit the aspects of pain which emerge, perhaps the very aspects that need to be elicited and which might not fit easily into pre-existing language.

Pain drawings are another measure currently in use, where patients are given outlines of the front and back of the human frame onto which they are asked to mark the site of their pain, often used with or as part of the MPQ. Pain clinicians have noted how patients regularly extend what could be a routine exercise turning it almost into a piece of artwork using different colours, shading, and symbols such as butterflies within the relevant area of the body (Pither 2002). Studies have shown how such drawings can give additional clues to what pain specialists term '*nonorganic factors*' in pain assessment (Uden et al. 1988 pp 389-92). It is widely accepted for example that the continuation of back pain reflects '*non organic*' as well as '*organic*' factors, such as social, occupational, and psychological factors. Addressing the difficulty of collecting information on these, Uden et al. proposed that drawings might elicit some of this information so speeding up differential diagnosis (ibid). They cite how markings made on the current pain drawing (on body outline) can help distinguish certain patterns of marks. For example, the specific pattern produced by a herniated lumbar disc in patients suffering from sciatica is usually different from those with widespread or non-anatomical pain, and shown to correlate with patients identified with concomitant psychological disturbances. Asserting that the organic process causing back pain is still mostly unknown and that psychological and socioeconomic factors are often present (ibid 1988 p 391), Uden et al. conclude that the pain drawing is a useful way to distinguish quickly between organic and non-organic pain, ie likely to become chronic and complex (ibid 1988 p 392). This has some parallels with Tracey's stated desire for an fMRI '*readout*' to help make the same distinction and differential diagnoses. One of the limits of Uden's tool is that patients were given pre-prescribed tools, here symbols/marks instead of words (six different symbols ranging between bars, dots and letters), which they could use to mark the pain drawings with, and it appears that if symbols were changed or not used according to the protocol the drawings were

discarded. I see this as a limitation as these might have been the very marks able to reveal what individual patients felt they needed to communicate.

Another interesting result of their study and one which makes an economic argument for looking at new approaches to the treatment of people with chronic pain, is their finding that the health insurance group (the study was conducted in Malmo, Scandinavia) showed more examples of non-organic pain than the outpatient and non patient group, consuming '*inordinate amounts of medical care*' and establishing what the authors describe as virtually a '*career of pain*'. They conclude that socioeconomic factors may prove to be of equal or even greater significance than psychological factors in the evolution of chronic pain (Uden et al. 1988, p 392, Vallfors 1985). What it also indicates is the pejorative language directed towards those whose pain has become complex and unremitting. Chronic pain undeniably puts pressure on the health services: the UK Government Survey of the NHS for 2011 reports 34% people as suffering from Chronic Pain. However, Arthur Kleinman argues his call for attention to be paid to social and psychological factors in a far less pejorative fashion (Kleinman 2008).

There is an urgent need to educate the public about chronic pain so that expectations are not unrealistically raised. One solution is to involve patients integrally in the design of their care and the eliciting and construction of the narrative that shapes understanding of their particular experience of continuing pain. Predetermined lists, figures and numerical scales and pejorative language do not provide adequate scope for this sort of partnership.

### **Examples of other medical studies using art to assess pain**

Extensions to the basic use of pain drawings have developed into many studies inviting patients, both adults and children,<sup>11</sup> to draw versions of their body in pain (Unruh et al. 1983, Wilkinson & Robinson 1985). One study asks children with sickle cell disease to do two drawings, one of themselves and one of themselves in pain (Stefanatou and Bowler 1997).

Drawing has also been used to identify anxiety in relation to pain and treatment in children undergoing dental treatment, with analyses of their drawings passed onto their paedodontists (Sheshkin et al. 1982). Some research has been done

specifically on the usefulness of children's drawings for diagnosing pain; pain charts and scales being developed using pictures or numbers, to describe their pain and/or drawings of pain (Stafstrom et al. 2005, Unruh et al.1983). A medical humanities student at Imperial College, London, Elena Roosinovich explored the use of children's drawings to help clinicians better understand their experiences with children on the wards at Charing Cross Hospital in 2008.

The British Pain Society in Liverpool, 2012, demonstrated the level of current interest in the use of images to communicate pain. For the last few years they have run an art competition in the main exhibiting area, attracting much interest with contributions from individuals and groups using image-making processes to explore the depiction of pain. One such group, the PainT Project, was set up by Dr Dietmar Harmann, a pain specialist in Dundee, with a team of art therapists. The consultant initiating the project is keen to continue the work, viewing it as having a beneficial effect on some of his patients. One of the reasons given for its impact by a colleague in her article in *Pain News* was: *'pain is generally expressed through pain behaviour, which is negative, limiting, imprisoning and disabling. An alternative expression (through art) liberates the sufferer from the prison of frustration, isolation and misunderstanding: "I am here" in colour'* (Geller 2011 p42). <sup>12b</sup> The workshops have finished but there are plans to hold bi-annual workshops in the future and participants contributed images to the Pain Society Art Exhibition 2012. The project focused more on self-expression than on communication as part of diagnoses or exploration of doctor-patient dialogue: *'Involvement in a creative art group gives patients with chronic pain empathic support, social inclusion and a means of expression for a nonverbal experience,'* building connections *'between the inner and outer world'* (Geller 2011 p 42). However, embedded in its rationale is an acute awareness of the difficulties of quantifying a subjective experience, such as pain, within the medical measures available.

There are various collections of online pain images worldwide such as PainExhibit<sup>13</sup> to which pain sufferers can contribute and share experience. PainExhibit is a prominent on-line site started in 2001 by Mark Collen. The first image in the collection was by Collen himself. The image is of a torn piece of paper on a black background with a small self-portrait photograph in the left hand corner, his face covered by brown paper with one eye peeping through a small hole within it (Collen 2001 and 2006, see

<http://painexhibit.org/galleries/mental-health>). The site is growing and now has more than 500 images contributed by people from all around the world, with PainExhibit, Inc. being established in June 2012 as a Californian non-profit Public Benefit Corporation. There is a well established history of websites and projects where women have given visual form to their experience of breast cancer, though not necessarily of physical pain. Even Pfizer has begun a collection of patient-created images of pain. Debate is ongoing about what they intend to do with them, and ethical concerns raised about how they might be used in the future.<sup>14</sup> My collaborator Joanna Zakrzewska and one of her students carried out a small study assessing migraine pain patients' moods using pre-existing artists images, such as Munch's scream (Chrysostomo et al 2004).

Another study recently completed by an MSc student from Durham, Sarah MacLean (MacLean 2010), cites the ***Perceptions of Pain*** work and material from our then unpublished paper ***a slippery surface***, now published (Padfield et al. 2010). She explores the use of patient drawings as a means of eliciting patient narrative and improving clinicians' understanding of their patients' pain experience. Building on the use of art established as an intervention in clinical consultations in ***Perceptions of Pain*** eight years earlier, MacLean's study concludes '*drawings do enhance the communication of chronic pain to healthcare professionals, providing benefits for patients and healthcare professionals. This enhanced communication is shown to lead to greater understanding by both the patient and their doctor of their chronic pain and its impact on their life*' (MacLean 2010, p 36). Her premise and thesis appear to draw heavily on the ***perceptions of pain*** publications, but instead of using photographs she concentrates on the use of drawing by patients themselves. It highlights for me the enthusiasm for taking up this sort of approach, the generative nature of my work and the benefits it could have for patients in the future. However, ***perceptions of pain*** remains the first study I know of in which photographs have been used within pain consultations to help in understanding the subjective experience of pain, with a view to improving doctor-patient communication. ***Face2face*** continues to expand this original research and deepen our understanding of its original hypothesis.

There is an increasing desire in people with chronic pain to make their pain visible to others. The research projects such as ***perceptions of pain*** and



**face2face** could be seen as having been generative of other research as well perhaps as being part of a movement arriving at a time when more focus is being accorded alternative approaches to managing chronic pain. However, none of the projects mentioned situate their work within a fine art context nor explore the specificities of the photographic medium's contribution to fine art and medical discourse.

No pain occurs in isolation. It occurs to a particular person, with a particular physiology, living in a particular culture at a particular moment in history and at a particular moment in their life. If photographic images can help elicit the most significant aspects of that person's pain experience, sometimes half-known, submerged in the depths of the sub-conscious - then these could surface into the light intersecting with the external world of medical diagnosis, and allow patients to contribute their unique insights to their own healing.

In discussing transgression, Shapiro explores the question '*are unruly narratives more authentic than conventional ones?*' (Shapiro, 2011). Over coherent narratives can be those which have become crystallised through telling and re-telling. What I hope images might do is to catalyse less rehearsed narratives, acting more like the '*intruders*' Jo Spence placed within her photographs - an object which disrupts the expected reading - encouraging spontaneous and original readings relevant at that moment, between those two people, within that consultation and at that point in the patients' journey (see page 125, Chapter two for a fuller discussion of the concept of an '*intruder*' within a visual image, also Spence 1986). What I hope our pain image cards can do is to trigger a more unruly dialogue, one which doesn't follow formulaic patterns, but can surprise both patient and clinician, leading them to places they didn't necessarily know they needed to go. (See chapter three for further analysis of their effect).

## **Narrative Medicine/Emotional Disclosure**

### **Rita Charon**

Prof Rita Charon first coined the phrase 'narrative medicine' (Charon, 2001) and is the most vocal and notable advocate of its value. She describes 'narrative medicine' as '*medicine practiced with the narrative competence to recognize, interpret, and be moved to action by the predicaments of others*' (2002 a). She

writes extensively (Charon 2001, 2002 a, 2002 b, 2004, 2005, 2008, 2010, Silva et al 2010 etc.) on the value of patient narrative within patient care and the importance of integrating an understanding of the 'lived' life into medical practice, of 'witnessing' the suffering of another. She has a poetic, insightful and empathetic slant on the spaces between the perspectives of: physician and patient; physician and self (an interesting one), physician and colleagues and physician and society. She argues that narrative competence allows physicians to reach out towards and join their patients in illness, claiming that *'by bridging the divides that separate physicians from patients, themselves, colleagues, and society, narrative medicine offers fresh opportunities for respectful, empathic, and nourishing medical care'* (Charon 2001 b).

Discussion of narrative medicine has been taken up by many others, notably Tricia Greenhalgh and Brian Hurwitz (Greenhalgh & Hurwitz 2010, Greenhalgh & Hurwitz 1999, Hurwitz 2000, Greenhalgh & Wengraf 2008) and by those who argue for patient-centred medicine such as my collaborator, Joanna Zakrzewska (2006, 2009a, 2009b). This summer (June 2013) sees a major narrative medicine conference take place in London<sup>12</sup> co-organised by Professor Brian Hurwitz and Professor Rita Charon (a collaboration between King's London and Columbia University New York) which considers the exciting developments in narrative medicine since its origination - at which ***duet for pain*** (Padfield 2012) will be screened - and the launch of an international network for narrative medicine. A resource of photographic images, such as the one being created during the ***face2face*** project, specifically designed to elicit narrative from pain patients, is another tool available to clinicians wishing to use a narrative based approach

Charon makes a fundamental point about narrative; *'built into the very nature of narrative is that it is shared'* (Charon 2005 p 30). It is the 'sharing' of narrative that to my mind makes it relevant to the consulting process and in particular consultations relating to chronic pain. Charon describes how she no longer elicits a history of present and past illness at the beginning of a consultation instead invites patients to tell her what they think she should know about their situation – in her words, she *'gives them the floor'* (Charon 2005, p 36). In so doing she recognises that what she is hearing are accounts of 'selves'. These accounts she transcribes as accurately as she can, using the language they used, and at the end of the consultation gives the patient a copy of this part of

the notes. This is an interesting development as so often the power of patients' own language is lost through translation into medical jargon, the medical notes differing widely from the vivid accounts patients have given (Marshall and Bleakley 2013). Charon follows it with more conventional information gathering but instead of framing this to fit within her own categories, it is framed within whatever system of meaning the patient has chosen to adopt (Charon 2005 p 36). This marks a significant change from conventional history taking where symptoms are assessed against existing constructs. Charon acknowledges that probably at some point in their interaction she would have learned some of these aspects of her patients lives, but:

*to have learned them in my first 20 minutes with the patient and to allow the patient to ascribe them pride of place as important aspects of their health gave me and the patient an edge, an advance, a fighting chance to become effective partners over the long haul in preserving and enhancing the patient's health* (Charon 2005, p 36).

Time constraints in the NHS are very real, but this goes some way to suggesting that although using the pain images to elicit narrative might take longer during a first consultation, if significant information can be elicited earlier, if what that person needs to communicate about their pain can be discovered, time can potentially be saved in the future (Padfield et al. 2010, Pither 2003). Napenas et al.'s study showed that patients valued an hour's consultation (Napena 2011) and I would argue that if images form part of this more lengthy initial consultation, significant information could be revealed, patient satisfaction increased and mutual trust improved, resulting in better adherence to jointly agreed treatment plans.

Charon asserts that 'medicine is confirming a growing understanding of the pivotal importance, in the outcomes of care, of *who* the patient is, *who* the doctor is, and the authentic relation and dialogue between them ' (Charon 2005, p 34). It is the subtleties of these dialogues that require attention. It is my hope that inserting visual images into that dialogue and analyzing their impact through video recording and evaluation forms, can not only reveal the way the image is functioning but reveal the finer textures of dialogue arising from conflicting perspectives. Charon places importance on what she sees as a new commitment to authenticity within the clinical relationship, describing it as 'a

*profound and daring recognition that illness calls forth the self – of the patient who suffers and the clinician who wants to help*’ (ibid p 34) – concluding that *‘the self is knowable only through stories’* (ibid p 34). I am not sure that the self is only knowable through stories, as for me this implies a linguistic coherence rather than the more open embodied route to ‘knowing’ that the visual arts can offer but I find her emphasis on the value of ‘telling’ and ‘listening’ very compelling. Listening is acknowledged by clinicians to improve trust and enhance success outcomes: *‘If we only listen well enough, the patient will give us the diagnosis, it is an old saying, it is nothing new’* (Zakrzewska in ***Duet for Pain***, Padfield 2012, Osler cited Sanders 2010 and Marshall & Bleakley 2013). Charon suggests that not only might one understand the meaning of symptoms through these stories, through telling and listening, but that the telling may in fact cure the illness (Charon 2005, p 32). In the same chapter she cites Steven Marcus (1975) who in an essay on Freud’s Dora suggested that *“illness amounts at least in part to suffering from an incoherent story or an inadequate narrative account of oneself”* (ibid p 32). Pain, as Professor Eric Cassell (Emeritus Professor of Public Health, Cornell University) asserts, is not confined either to the body or a single point in time, it happens when *‘an impending destruction of the person is perceived, it continues until the threat of disintegration has passed or until the integrity of the person has been restored’* (Cassell 1991). His argument supports Charon’s conceptualisation of the creation or re-creation of a coherent narrative of the self as a necessary constituent in the healing process.

### **Johanna Shapiro and John Sarno**

Shapiro warns of some of the dangers of trying to superimpose coherence on patient narratives, or judging them for their authenticity or reliability, arguing instead that there is a need for humility in their witnessing, that in hearing and witnessing these ‘stories’, *‘professionals should respect that patients tell the stories they need to tell’* (Shapiro 2011). Doctors frequently convert the narrative they hear into medical jargon so that much of their power is lost; the evidence is in the medical notes written up after consultations. (Marshall & Bleakley 2013) Could the images be a way of involving clinician and patient in building a different sort of language together, albeit dependent on the experience of the clinician to feel comfortable doing this.

The cards could similarly be seen as a complement to John Sarno's technique of 'emotional disclosure' used by some clinics. Since John Sarno's (1998) seminal work on the value of emotional disclosure and the integral relationship between mind and body, many studies and programmes have introduced short courses using a variety of emotional disclosure techniques for patients with long-term pain. These claim a link between opportunities offered for expression and discussion of emotion with improved physical health (Broderick et al. 2005, Smyth et al. 2003, Hsu et al. 2010). Many of the papers also make a correlating link between suppressed emotional experience and high levels of pain (Brosschott et al. 2001, Hsu et al. 2010). This raises concerns for me reminiscent of Sontag's warnings of earlier characterisations of '*cancer types*', of cancer caused by '*suppressed emotion*' that only add guilt onto the suffering already experienced by sufferers. Proponents of 'emotional disclosure' suggest that highly charged emotional experience can affect the central nervous system so contributing to and maintaining the intensity of pain. If this is verifiable, then it does follow logically that facilitating discussion and disclosure of emotional experience and emotional pain could help reduce actual physiological pain, although as a non-scientist or specialist in this field, I need to be convinced of the reliability of the evidence for this as it is beyond my expertise. Photographs, as we are beginning to witness in the **face2face** study, are an excellent way to catalyse 'emotional disclosure' where appropriate - their immediacy allowing patients quick access to underlying emotions. Conversely, the power of images to elicit emotional responses should be remembered and their use approached with caution, sensitivity and within safe boundaries. In their fascinating recent paper (2010) on an emotional disclosure intervention with a study and control group of fibromyalgia patients, Hsu and his colleagues attribute the relative lack of efficacy of current treatments for fibromyalgia to a lack of emphasis placed on '*psychological stress regulation of affect*'. They explain how early stress events such as abuse, childhood trauma or victimization and adult stresses such as marital and work difficulties can exacerbate and contribute to intense unresolved pain. They describe how they therefore developed a treatment approach focusing specifically on emotional factors (Hsu et al. 2010). There are many additional papers showing that risk factors for chronicity include significant childhood and life events and depression (Fillingim et al. 2011, Conrad et al. 2007, Imbierowicz et al. 2003, Davies et al. 2009). I believe that if these claims are accurate then they support the thesis that using photographic images within pain consultations could equally result in a physiological reduction of pain. I

would cautiously submit that the resource of photographic images of different qualities of pain developed during **face2face** can complement and contribute to emotional disclosure and narrative practices.

## COMMUNICATION – DIALOGUE – LANGUAGE

### Can pain be put into words?

*'You must think about the purpose of words ... What does language have to do with pain?'* (Wittgenstein 1980 p112). Pain has everything and yet nothing to do with language. Scarry has famously asserted that it resists language: *'Physical pain does not simply resist language but actively destroys it, bringing about a state anterior to language, to the sounds and cries a human being makes before language is learned'* (Scarry 1985 p 4). She describes pain as *'shattering'* (ibid p5) language, focusing on two causes for pain's resistance to communicability. One reason she gives is that pain *'unlike any other state of consciousness – has no referential content. It is not of or for anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language'* (ibid p5). But does pain have no referential content? The images created during **face2face** and the narratives within them rather belie this. The narratives they elicit suggest there might be many, though not necessarily obvious, objects for their pain and frequently those with pain attribute it to situations, events, even figures in their lives. The other reason Scarry highlights is the commonly acknowledged uncertainty that hearing about another person's pain engenders in the other, ie that we come to descriptions of pain with doubt: *'to have great pain is to have certainty; to hear that another person has pain is to have doubt (the doubt of other persons, here as elsewhere, amplifies the suffering of those already in pain'* (Scarry 1985 p 7).

That pain is difficult to describe in language I fully concur with. American physician and academic David Biro positions language and pain as *'far apart as the opposite poles of an electric current'* (Biro 2010 p 11). As a chronic pain sufferer myself, I know only too well the isolation and frustration caused by constant pain; the difficulty it presents to communication; the disbelief and uncertainty of others; and the certainty of its unremitting toll on the self and increased self-doubt it nurtures. Many of the patients I worked with on both

projects described not only a difficulty of finding language capable of expressing their sensations but a frustration with trying to get others, particularly their doctors, to believe them. It is one of the most frequently given reasons for participating in **perceptions of pain** and **face2face**.

*'I have always found it hard to explain my pain to doctors. You have to explain it to them so that they can understand it, and it doesn't matter how often you try to explain it to them, they still don't understand'* (**perceptions of pain** participating patient, Padfield 2003 p 17).

*'You can't see pain, so people don't believe it. I had that even more so with doctors. One doctor sat there and said, "You cannot be in the pain you say you are in, "I said, "What do you want me to do to show you I am in pain?"' (ibid).*

*'I think in some cultures pain isn't acknowledged and illness isn't acknowledged ... I remember being told "you can't be in pain because children don't get pain, you're too young" and then later it would be, "you know, maybe, you're just feeling sorry for yourself" would come from people, not necessarily family, but unfortunately from doctors.'* (**face2face** participating patient).

It is paralleled by the counter-narratives reported verbatim from doctors cited in Kenny's study of doctor-patient interaction (2004 p 301): *Some people actually believe what they are telling you. . . but you just couldn't believe that they were unable to do some small physical task because of the pain they were in.'* From another doctor: *'It stands to reason. If you have done all the tests possible, and you get nothing, not a hint of a physical problem, what else can you conclude?*

Scarry is absolutely right to draw our attention to the difficulties pain presents for language, and to what is at stake when attempting to create a language with which to communicate it; the objectification which might result, the ethical questions raised for those speaking 'on behalf of others' in pain (such as myself), the dangers of bypassing the 'fragments' of descriptions patients produce in a search for coherence and the lack of trust shown by some of the medical profession in the reliability of these fragmentary words which struggle to construct concrete form from something as 'slippery' and invisible as pain.

There are still no x-rays, no unequivocal medical imaging techniques to validate the existence of pain. Pain is a prime example where one might, with Eliot, say:

*Words strain,  
Crack and sometimes break, under the burden,  
Under the tension, slip, slide, perish,  
Decay with imprecision ...*

(T.S.Eliot, The Four Quartets)

### **Pain as generating language**

That pain destroys language is only partially true. The historian Joanna Bourke believes that pain far from destroying language actively generates language (Bourke 2011 a, p6). Bourke believes that new language is formed in the attempt to articulate pain, in particular through the creation and use of metaphor, so often employed in descriptions of pain. She cites Virginia Woolf, who while complaining of the '*poverty of the language of pain*', also describes how a person in pain '*is forced to coin words himself*' (Woolf 1930 p 7). To some extent I agree that the struggle to find words pushes sufferers to new ways of communicating, frequently to metaphor. Academic and physician David Biro claims that whenever we are confronted '*with something difficult or impossible to grasp, there is only one way open to us: metaphor*' (Biro 2010 p 16). However in my view these are often well-used and over-worn metaphors, such as a hammer on the head, the stab of a knife - which tell us little about an individual's unique experience of pain. Pain specialist Charles Pither told me when we first started working together that no one who had actually been stabbed with a knife had ever described it as such (see also Miller 2005). I believe these metaphors tell us more about our current cultural attitudes to pain than about an individual's personal experience of pain. Linguist Elena Semino's fascinating analyses of pain metaphors highlights the prevalence of metaphors of agency, violence, active injury and physical damage (Semino 2010 2013). This observation is echoed by David Biro in *the language of pain* where in chapter six he concentrates on the symbol of the weapon, observing how people tend to describe their pain in terms of potential weapons such as knives, hammers, vices, and fire (Biro 2010 p 80). Interestingly many of these weapons feature in



the images created during **perceptions of pain** (See figs 7 and 8). Biro goes on throughout the rest of his very readable book to counter Woolf's assertion that pain has caused language to run dry, through his own attempt to '*restore its flow*' (Biro 2010 p 14). There is perhaps a potency at the intersect of pain, language and image. Where I have witnessed new language being born in response to pain, if it is not too vast a claim, is in the space between language and image, between linguistic and visual metaphor, catalysed by both the **face2face** image cards and the image-making process.

### **Space between word and image**

During the **face2face** project consultation recordings we have viewed patients referencing and handling photographs of pain but responding with words. It is almost as if, as artist and academic Jane Wildgoose described in an early review of **perceptions of pain** (Lancet 2002):

*Concentrating from the outset on visual language, the project also successfully reinvigorates verbal narrative. The photographs are powerful and compelling; they draw you into an imaginative world that is not always immediately comprehensible and lead the viewer to the text for more insights, and then back again to the image... (Wildgoose 2002).*

Something is created in the space between word and image which re-invigorates both, and which draws attention to the process of negotiation, not just between art forms, but between speakers.

Language is not itself a neutral conveyor of facts. It is not sufficient to understand language as transparent or purely reflective, '*rather, language is constitutive: it is the site where meanings are created and changed*' (Taylor 2003 p6). It is a co-constructed process and I believe that consequently attention has to be paid by all speakers to their own role in the re-presenting and the re-constructing of a pain narrative – and that includes my own role discussing the images as we co-create them. The pain narrative is being created in the medical consulting room via its 'telling' and its 'witnessing'. If images can equalise the space and process of this telling, then they are a worthwhile venture - not detracting from verbal descriptors but expanding them. Perhaps it is not the images themselves which form an alternative language for

pain, as I first imagined when working on **perceptions of pain**, but the space between language and image which while re-invigorating and re-inventing language is allowing the formation of a new 'language for pain'. If language is mediated via the image, can this process of mediation bring into being a new language with which to share the experience of pain?

*To witness the moment when pain causes a reversion to the pre-language cries and groans is to witness the destruction of language; but conversely, to be present when a person moves up out of that pre-language and projects the facts of sentience into speech is almost to have been permitted to be present at the birth of language itself. (Scarry 1985 p 6).*

Can images encourage a broadening and a sharing of understanding, capturing something of an embodied as opposed to theoretical understanding of pain, transforming the way we are able to communicate and understand it? The linguist Stephanie Taylor, discussing definitions of language, reminds us that it is not reflective in a static or absolute way, asking should language be treated as referential or as constitutive? Taylor reminds us that language is a means for doing things, for example, persuading, sowing the seeds of doubt, or rapport building, and that it is situated within a particular interaction (Taylor 2003, p 7). We cannot take the language used within a consultation therefore as simply conveying meaning from one speaker to another, there is a relationship, meaning and 'reality' which is being constructed and negotiated through the physical sounds and exchange of language, and if we insert images into that language, also via the relationship between image and language.

Image and text (and here I mean spoken as much as written text) have a relationship with and responsibility to each other, and doctors and patients have an active responsibility towards the language emerging and dialogue constructed. Joanna Zakrzewska articulates this from a clinical perspective: *'The language that we as clinicians use is sometimes inducing problems because it causes harm as well and that is what is beautifully brought out in narrative medicine'* (Zakrzewska in **facing pain**, Padfield 2011). I feel patients also have to take responsibility for the language they use and narratives they construct. If pain results from an *'incoherent narrative'* as Charon asserts, then we have to pay great attention to how that narrative is made coherent, making

sure it is the person with pain, who is taking the lead in its 're-construction' and its 're-presentation'. A challenge to this may lie in the difficulty for some doctors in accepting what they perceive as 'defeat'. In sociologist Dianna Kenny's study of doctor-patient communication she quotes one doctor as saying: "*But honestly, it can be a thankless task working with chronic pain patients. Who wants to be confronted with failure every day?*" (Kenny 2004 p 302) in Kenny's words chronic pain patients '*fail the test of the good patient. They do not get better.*' (ibid p 302). For many doctors it is challenging to accept they cannot produce a cure for pain, that a successful outcome of interaction with their patient might be improved understanding, reduced isolation, a 'sharing' of experience or making sense of sensation, rather than cure, all of which are language dependent (Charon 2005). All these also make huge demands on the clinician. Another doctor from Kenny's study (2004) responded: '*By the time many patients get to us there has been a lot of damage done. There is a limit to what we can do. So many have significant barriers to recovery at this stage, it is difficult to get motivated to help them*' (ibid p 301).

Language is dynamic, forever evolving within specific personal interactions as well as institutionally, culturally and inter-culturally. Pain too exists within fluctuating personal and collective schemas. Language and pain can both be characterised as fluctuating systems, paralleled by the way pain itself involves a set of plastic systems within the brain and the body, interacting with a "self" in flux. If that 'self' has the capacity to modulate and modify its own pain, then there is an implicit recognition that the doctor's role has moved from 'cure' towards a facilitation of healing (Padfield et al. 2010) - healing of, for want of a better word, the 'self'. Without effective collaborative communication, and equalised dialogue - how can any such healing of the 'self' take place in a consulting context? How many clinicians are equipped to accompany someone on a journey as daunting as the recovery of a 'self' or have the ability to interpret what they hear? Can we realistically expect this from our doctors?

*The task of physicians and surgeons is to correct or repair the damage. But, recognizing the intrinsically personal nature of pain and suffering, the doctors' remit equally embraces the self.*

(Broks 2004)

My collaborator, facial pain specialist Joanna Zakrzewska, is one clinician willing to go on such a journey with her patients; describing their pain as a rucksack, she relates their journey on a path up a mountain littered with obstacles, shrubs and bushes which she sees herself helping them to cut down (Zakrzewska in *facing pain*, Padfield 2011). She also acknowledges the effect of this on physicians and the need for them to regularly '*get together and offload*' (ibid). More and more clinicians are seeing their interaction with patients as important, hence the development of multidisciplinary pain clinics to encompass a wider perspective. In the context of physicians being asked to heal the 'self', good communication becomes not 'a luxurious by product', but an essential component of consulting (Kenny 2004).

### **Effective two-way communication**

Although '*the medical literature on pain regularly addresses the issue of how to overcome the communicative difficulties experienced by sufferers, especially in the case of chronic pain*' (Semino 2012 p 269) and communication skills are commonly taught as part of the medical curriculum, ineffective communication remains a barrier to adequate assessment, understanding and treatment of pain (Kimberlin 2004, Yates et al. 2002). Direction of the dialogue is not always equally shared. The interaction between patient and clinician is pivotal in the chronic pain journey and in the successful unraveling of meaning and subsequent appropriate referral. The dynamics and patterns of language are instrumental in maintaining unequalled dialogue and imbalanced power-relations. Prof. Alan Bleakley has written widely on the benefits of more democratized dialogue, and been instrumental in incorporating this into medical training at Peninsula Medical School (Bleakley 2006 2012, Marshall & Bleakley 2013). Sociologist Dianna Kenny has written a fascinating paper examining interactions between doctors and chronic pain patients with medically unexplained pain (Kenny 2004), which exposes an implicit dialogue between doctors and patients undermining the quality of their interactions, challenging each other's credibility and causing distress to both parties. She cites the implicit dialogue of the chronic pain patient as being based on biogenic theory while that of doctors as underpinned by psychogenic theory. The impasse at the beginning of many pain consultations is explained as, at least in part, due to different agendas: patients searching for a mechanical and clinicians for a

psychogenic explanation of the pain. Kenny concludes that *'the argument about whether the cause of the pain was physical or psychological was the fundamental source of disagreement between doctors and chronic pain patients'* (Kenny 2004, p301). She expands by demonstrating that there *'is much more invested in these consultations than a correct diagnosis,'* reflecting that *'herein lies a possible explanation as to why doctors and patients alike continue to engage in exhausting rituals that leave both parties depleted'* (ibid, p 303). They are struggling to maintain their identity and integrity and it is largely through language that they are attempting to do this. She concludes by observing that *'potentially healing interactions between doctors and their patients need to be found that do not rely on the biogenic model of the visible body or the psychogenic model of invisible pain'* (Kenny 2004, p 297 - 305). She argues for new paradigms which integrate the biological, psychological and social/systemic elements of the pain experience to guide chronic pain management in future (Kenny 2004, p304).

The lengthy discussions of pain encompassing all these aspects that I have had during the individual workshops sessions with facial pain patients during **face2face** reaffirm this imperative for me. In trying, for example, to give visual form to a shadow sandwich as a metaphor for pain, (see figs 2, 9 and 29) our conversation traversed social contexts, physical experiences as well as emotional significance and psychological responses; neither on their own would convey the complexity of the experience:

*I'd got, the kind of stifling... feeling, merging into something not quite right ... I kind of felt like maybe I should have said ghost, rather than shadow, because you know when you say kind of a shadow or a ghost of who you were, that's what I meant ... what would be the skin, is really the mouldy bit. And that's what I was thinking wasn't necessarily in the shadow, when it was really black, was the kind of festering feeling in it, but that does get it. Cognitive impairment, your memory not being able to function properly, just like fatigue ... it's just the most bizarre experience when your face muscles aren't moving and, your speech muscles are going wrong ... It's interesting, you know my hands are trying to reach out but, you know in some ways you become unreachable. And that also alienates you, - that's such an alien image.*

*... it's a horrible thing, but it's like a death that comes over your life because you lose so much time .... (Study Code W5)*

Kenny finds consciousness and constructivist frameworks useful models in this context. She references Chapman et al. (1999), who argue:

*that the brain deals not with reality itself (in the case of pain, nociception), but with an internal representation of reality that it constructs from sensory information, prior experiences, memories and meaning making. According to this model, pain emerges from complex patterns of massive parallel distributed processing in the perceiver's model of the self and world (Chapman 1999, p. 45, cited Kenny 2004, p 304).*

The images created during **face2face** give us glimpses of such representations of reality, moving them out of the internal arenas of the brain and into the external arena of the art workshop and the consulting room. Supported by current theories of plasticity - ie that pain both influences and is influenced by its own process - is it worth evaluating a tool which can help elicit aspects most significant to an individual's pain picture and integrate these within biogenic models?

In fact it has to be worth investigating any technique with the potential to improve mutually beneficial communication between doctor and patient which could facilitate what Charon would call 'authentic dialogue', helping it veer away from pre-set patterns. Images as an intervention within the consulting room, like any intervention, are likely to encourage the dialogue to enter uncharted territory, rendering them agents for transformation? In her analysis of doctor-patient dialogue Kenny provides evidence of attempts by speakers from both groups to ensure that their version of events is correct and prevails over competing versions, citing the success of this as a common goal of account giving. A negotiated dialogue using an image as stimulus is one way of moving away from a pattern of making one's own version prevail, at the expense of another's. The ambiguity of the image forces patient and clinician to negotiate their understanding of it, and thus negotiate the narrative constructed around it encouraging a tolerance of different perspectives and a collaborative approach to dialogue.

*'Whatever pain achieves, it achieves in part through its unsharability and it ensures this unsharability through its resistance to language'* (Scarry 1985, p 4). If Scarry's seminal statement is correct and pain's unsharability is one of its defences against communication in language, and I believe this to be so, then we have to find a means of reducing its 'unsharability'. Introducing images into dialogue to interact with language might be one means of doing this. David Biro writes of the amorphousness of pain through it not being connected to objects, stating that *'by not being connected to objects in the shared world, it resists meaning and language'* (Biro 2010 p 41). Despite its apparent resistance to language, it is with language that we search to find ways of sharing pain, generally moving from the familiar to the less familiar, the sharable to the less sharable, via metaphor, which will be the focus of the last part of this chapter.

## **FIGURATIVE LANGUAGE FOR PAIN**

It is well recognized by medical professionals that figurative language is often used by patients when trying to communicate what their pain feels like (Semino 2013). What is significant about the images and pain cards is that they are not purely literary or linguistic metaphors, they are additionally visual metaphors. Consequently they have a materiality which allows them to reference sensation and emotion, to draw forth a physical response reaching beyond the domains of language to something more primal and less linearly coherent. We see them with our eyes, we react to them against a certain background and in a certain context, they act as signifiers denoting and connoting beyond their frame, they have a surface which reflects and a shape and size we handle, a depth within the image and within the card of which they are made, they have colour and texture; we hand them back and forth and they become part of an enacted exchange, a 'performance' – they have in short their own agency (See fig 10). There is a general move from Gell, through Tilley, Miller, Pinney and other anthropologists to consider and give importance to the materiality of art objects. Metaphorical processes according to anthropologist Christopher Tilley do not mediate between, but are constitutive of, both sensual experience and abstract thought. Without metaphor, Tilley argues, human communication would be *'nigh impossible'*. It is metaphors which provide a basis for an interpretative understanding of the world, the goal of most historical and social sciences (Tilley

1999, p 11). If we are attempting to understand the world of pain, its resistance to language, and we are seeking an alternative visual language with which to capture it, it is worth first exploring the limits and potential of metaphor in its broadest sense, and what visuality and materiality can add to linguistic metaphor as a mode of communication for pain.

## Metaphor

Aristotle defines metaphor as a mismatching or transference of names, perceiving language as mapping onto the world in a one-to-one correspondence between names and objects. In the Poetics he writes '*metaphor consists in giving the thing a name which belongs to something else (allogrios)*' or as the *transposition of an "alien name"* (Barnes ed 1984). The OED still defines metaphor in terms of substitution, a '*figure of speech in which a name or descriptive term is transferred to some object to which it is not properly applicable*'. (For a full discussion of Aristotle's definition of metaphor, see Morris 2000 pp 105 -108). Contemporary theorists build on Aristotle's 'substitution theory', adding in interactive and extra-linguistic elements to their definition believing language to play a more constitutive than illustrative role in our versions of reality, exchanging terms such as 'schema' and 'category' for 'names'.

*Now metaphor typically involves a change not merely of range but also of realm. A label along with others constituting a schema is in effect detached from the home realm of that schema and applied for the sorting and organizing of an alien realm ... A schema may be transported almost anywhere. The choice of territory for invasion is arbitrary; but the operation within that territory is almost never completely so (Goodman 1976 pp 72-74).*

However we retain Aristotle's sense of substitution, very basically we use metaphor to talk about something in terms of something else. When there are no existing words to convey a sensation adequately, such as pain, it is no surprise that we often turn to metaphor, what else do we have? In contrast to Sontag's claim '*that illness is not a metaphor, and that the most truthful way of*



*regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking*' (Sontag 1978, p3), David Biro suggests that as there is '*no literal language*' for pain, it is either metaphor or nothing (Biro 2010).

*Pain is an all-consuming internal experience that threatens to destroy everything except itself and can only be described metaphorically.* (Biro 2011 p109).

Biro observes an interesting symmetry between pain and metaphor drawing a parallel between pain as a deviant in respect to health, and metaphor as a deviant from ordinary language. (See Levin 1977 and Cohen 1979 for fuller descriptions of deviancy in relation to metaphor).<sup>15</sup> Although many, such as Lakoff and Johnson (1980, 1993) and Gibbs (1999), argue metaphorical expression is a natural part of language and not an unusual or deviant phenomenon.<sup>15</sup>

Many historic depictions of pain are of faces unable to speak, of a silent scream, Scarry for example cites the paintings of Eisenstein, Stanzione and Munch's celebrated image (see fig 11a) (some of the images from ***perceptions of pain*** and ***face2face*** also depict mouths without language, see fig 11b). What happens when we try to break this silence and give form to pain? Metaphor. Etymologically metaphor, coming from the Greek –'*meta*' – and '*pherein*', means to '*transfer*' and '*carry beyond*' (Bourke 2011 a) or '*bear across*'. Metaphor allows us to go beyond the literal, to incorporate feelings, emotions and visualisations into a description which can be understood by another. According to Biro there is a disconnect between the external knowable world and the internal world of our bodies that most of us have little knowledge of and which forces us to more indirect ways of speaking and thinking to reflect its sensations (Biro 2010, 2011). He argues it is not that there are not enough words, it is more that the experience of pain is too blurry and too hard to pin down within them. Biro claims (and many support this) that we think of pain in terms of what is knowable, mainly in terms of weaponry or physical injury, so a pain is described as 'sharp' or 'stabbing' like a knife. This forces us towards metaphor as a way of inserting these knowable objects into what is essentially unknowable, ie we have to incorporate them into more imaginative and literary modes of expression to capture that which is far less tangible than a knife.

Metaphor, according to Biro, creates the referents missing from pain onto which we can hang its elusive attributes. Metaphor expands what we can do with language allowing us to go beyond the literal and approach elusive sensation though giving it meaning. Linguist Elena Semino's definition of metaphor as *'varied in its textual manifestations, versatile in the functions it may perform, and central to many different types of communication, from informal interaction through political speeches to scientific theorizing'* supports this (Semino 2013). Her analysis of metaphor converges with Biro's in emphasising *'the tendency towards an interaction between conventionality and creativity in metaphor use'* (ibid), and it is in its leanings towards creativity that it intersects with the **face2face** project and the representation of the invisible experience of pain.

## Analogy

Melzack and Torgerson (1971), in their research into the language of pain (which later developed into the McGill Pain Questionnaire, MPQ), noted the common use of analogy in patients' pain descriptions. Analogy, inferring similarity in *'attributes, circumstances, relations or uses'* (OED definition), is a form of metaphor, but is generally taken as more complex, implying some sort of logical argument suggesting that if two things are similar in some ways, then they may also be similar in others. It is easy to see why analogy appeals to those searching for ways to describe their pain. If one takes Biro, Bourke and Semino's category of weaponry/injury metaphors it follows that if a particular pain were analogous to a knife wound, it would imply the pain was caused by tissue damage, by an outside aggressive agent, the result of some form of violence to the self. Melzack and Torgerson observed that for each word patients used to describe their pain, there were usually two meanings, the literal meaning and the 'as if...' meaning, for example the head felt 'as if' it was being split open, concluding that pain descriptions frequently involve analogy. Pain descriptions therefore do not necessarily divide up neatly into literal or figurative language, they are inherently both. Dr Jonathon Miller discusses the figurative nature of pain reports in *The Body in Question* (2000). Of being stabbed with a knife (as Pither also noted), Miller observes that few of us know what this actually feels like, concluding that when describing his/her pain as such *'the patient has extracted from his idea of stabbing an image of violent penetration which he uses in a metaphorical way to extend to his own pain.'* (Miller 2000, p

38). In the words of Geoffrey Schott, a neurologist from the National Hospital for Neurology and Neurosurgery, London:

*Attempts to truly describe pain indeed appear as difficult as they are frustrating, yet the need to communicate is overwhelming, and I suggest that the only option available is the resort to analogy ... whether by means of metaphor or simile.* '(Schott 2004 p 210 cited Semino 2013 p 269).

## **Simile**

A simile compares two different things, using 'like' or 'as' to create a new meaning, and is often used in descriptions of pain, where sufferers search for a common external object with which to describe a unique inner experience, for example it feels 'like' being stabbed by a knife, it is like 'fire'. The use of 'like' can dilute its impact, in a way which is not the case for direct metaphor. Morris (2000) articulates the difference between simile and metaphor through reference to Aristotle's *Art of Rhetoric* which, she argues, defines metaphor as a form of collapsed simile, reinforcing the iconic relation of 'similarity' as intrinsic to the creation of metaphor :

*When the poet says of Achilles that he "Leapt on the foe as a lion," this is a simile ; when he says of him "the lion leapt," it is a metaphor - here, since both are courageous, [Homer] has transferred to Achilles the name of a "lion". (1406 b 20-3) [not my insert]*

## **Metonymy**

Semino (2013) asserts that both conventional and creative figurative language provide the image content '*pain lacks when there is no visible tissue damage*' expressing '*at least to some extent, what would otherwise be difficult ... to communicate, and for others to accept as real*' (ibid p 269). Metonymy is the substitution of the name of an attribute of a thing with which it is associated, for the thing meant, eg a suit for a business/city person, or Westminster for the Houses of Parliament. Semino describes how some of the words in the McGill Pain Questionnaire work metonymically. Taking as an example 'searing' in the context of a description of torture cited in a text taken from the British National

Corpus (BNC), Semino observes that the first time the term is used it is a literal description of torture '*burning the skin*', but the second time the term is used in the same passage it is not literal in the sense of a literal process of burning the skin but is used to '*describe the pain sensation that results from the tissue damage caused by the application of the hot pokers to the skin*' (Semino 2013 p 270).

She argues that here the cause of the tissue damage stands in for the quality of the pain that results from it, and can thus be described as metonymic. She compares this with pain associated with migraine described as 'searing', where there are no actual burning objects but the association of searing with tissue damage is employed to describe the quality of the pain sensation. This she defines as metaphor but claims it has its basis in the '*metonymic association between the cause of tissue damage and the result of tissue damage in terms of physical sensations*' (Semino 2013 p 270). Metonymy here not only facilitates communication of an internal and subjective experience but as with the many other figurative uses of weaponry terms, links pain experience with actual physical harm, cementing a causal link between perceived pain and injury. Of the 78 words in the MPQ, Semino identifies 10 as working metonymically (ibid p276). She describes a heavy reliance on both metaphor and metonymy in the images and their accompanying texts in ***perceptions of pain*** (Padfield 2003) deciding to use the term '*figurative communication*' to capture the '*multimodal use of metaphor and metonymy*' in what she terms '*Padfield's book*' (Semino 2013 p 282).

### **Catachresis**

Catachresis as a rhetorical figure provided names for things which have no name. Citing Aristotle's definition of catachresis as fulfilling a perceived need to extend language - because of an asymmetry between language (*which is finite*) and the world (*which is infinite*) which concluded that eventually we will run out of words and so need to extend the meaning of existing words to cover additional objects for example the 'leg' of a table,<sup>16</sup> David Biro proposes it is the optimum class of metaphor for thinking about pain (2010 p 73). He conceives catachresis as bringing new conceptions into being through language we already know. He also interestingly equates the void or absence catachresis fills with the void or absence pain sufferers experience. Biro acknowledges that this

type of language extension does not capture the complexity and cognitive dimensions of more complex metaphors however. I believe this is why we need visual metaphors, which, through the plurality of meanings they offer, allow us to come closer to capturing sensations as complex and difficult to capture in language as pain. The next section will run through changing metaphors for pain and the schemas they reflect historically, through literary metaphors for pain to the use of visual metaphors, arguing their materiality with its direct access to sensation renders them the most able to capture the multidimensional experience that is pain.

## CHANGING METAPHORS AND SCHEMAS FOR PAIN:

### HISTORICAL METAPHORS FOR PAIN

Many academics, most notably Professor of History at Birkbeck, Joanna Bourke, argue that metaphors for pain have changed over time. This raises the question has the experience they describe also changed over time? In other words does the language *constitute* change in experience, *reflect change* in experience, both or neither?

*People choose their metaphors 'not as "contained", isolated, individual bodies, but in interaction with other bodies and environments. In the context of pain, for example, it makes a difference whether pain was inflicted by an infuriated deity, was due to imbalance in the ebb and flow of humours, was a result of an invasion by a germ, or emerged after a lifetime of bad habits (Bourke 2011a, p17).*

Reading much of the literature and in particular Joanna Bourke's comprehensive work on the history of pain (Bourke 2011 a, 2011 b), it is almost impossible to doubt that pain is experienced differently according to its social and historical context. Looking at the images we created during both **perceptions of pain** and **face2face** it is impossible to fully accept it. The images in both these projects appear to reflect aspects of all of the following: metaphors of humoral theory, metaphors of punishment and retribution from Christian/religious frameworks, metaphors of machinery and electricity from the industrialised ages and

metaphors of invasion and attack from the twentieth century. So how much have the metaphors patients resort to really changed? One can ask are there some aspects so primal that they parallel the primal aspects of the pain experience, taking us back to Scarry's sounds and cries an infant makes 'anterior to language' (1985)? Conversely, could metaphors reflect the attitudes of different historical periods precisely because there was so little knowledge of actual pain processes to resort to, leaving only metaphor as a means of describing them? Susan Sontag suggests that the application of metaphor to TB and to cancer occurred while both diseases were still shrouded in mystique (Sontag 1978). Once TB was understood as an infection which could be cured, then Sontag claims the metaphors for TB and Cancer were able to become truly distinct (Sontag 1978 p11). Of TB she writes ' *the power of the myth was dispelled only when proper treatment was finally developed, with the discovery of streptomycin in 1944 and the introduction of isoniazid in 1952* (Sontag 1978p 35). Could one reason we apply metaphor to pain also be because its myth has not yet been dispelled? When and if we fully understand pain, might metaphor's dominion over the language of pain have to be relinquished? Alternatively, is pain the result of a more complex interaction of processes for which there is unlikely to be a simple 'cure' and metaphor may remain the best option for conveying it?

### **Ancient Schemas**

In Ancient Greece, disease and pain was seen as divine wrath meted out to individuals or communities. Susan Sontag cites the following examples: Book I of the Iliad where Apollo inflicts the plague on the Achaeans as punishment for Agamemnon's abduction of Chryses' daughter; or the plague which strikes Thebes because of the royal sinner, or in the case of an individual, the stinking wound in Philoctetes' foot (Sontag 1978 p 40). Sontag claims that even where disease isn't held to be a judgement on a community initially, it becomes one retroactively – collapsing morals and manners, for example Thucydides relates the plague breaking out in Athens in 430 b.c. as '*spawning disorder and lawlessness*' (Sontag 1978 p41). Pain, suffering and disease existed in the overlap between moral and physical dimensions.

## Humoural Theory

From the Middle Ages up until the nineteenth century, humoural theory dominated much of medical theory in Europe. Humoural metaphors were characterised by ebbs and flows, by movement or blockage and pain conceived as the result of having too much or too little of the four fluids; phlegm, black bile, yellow bile, and blood (Bourke 2011a p 26). There is an interesting comparison with the metaphors of 'stuckness' and blockage, (physical and psychological), evident in the contemporary images created during the **face2face** project, and its forerunner **Perceptions of pain**. In these projects there are images of cement mixers blocked by brick walls and steps, of concrete jackets restraining movement, of legs too large to go through an exit, and slices of bread trapping an identity between them (see figs 4, 5, 6 and 12). I have interpreted these metaphors of blockage as reflecting the 'stuckness' that pervades so many consultations explained by the differing frustrations and agendas of patient and clinician thwarting movement. It is possible however they reference sensations of flow and blockage redolent of humoural theory underlying pain perception more universally.

Compare for example historian Ulinka Rublack's explanation of the body-view in humoural theory as:

*not regarded as a whole and clearly delimited entity, but rather... understood as something that was constantly changing, absorbing and excreting, flowing, sweating, being bled, cupped and purged. It was clearly situated in the continually-changing context of a relationship to the world whose precise effect was never stable or predictable, so that one simply had to submit to it – to the terror that froze the blood, [and to] the sudden trembling, bleeding, or urination. (Rublack 2002, cited Bourke 2011a p26)*

with the following sentiment of a pain sufferer quoted in **Perceptions of Pain** (Padfield 2003 p 37):

*The feeling began in my feet. I awoke to a feeling of intense cold growing through my feet. It felt as if my veins had turned to ice – and were pushing freezing water around my body ... Thankfully the sensation*

*did not get any further than my ankles ... I was afraid that my whole body might become frozen – that I would turn into a block of ice*

Although medical conception has changed radically from humoral theory, have we as patients or subjects moved away from this or have some of these notions remain buried within our psyches emerging unconsciously in visualisations of the limitations pain puts on us?

In his lecture '*A normal psychology for pain*' at the Pain Society Annual Scientific Meeting in Liverpool 2012, psychologist Professor Christopher Eccleston challenged the commonly held perception of pain as a position of blockage or lack of movement. Instead he asserted that pain generates movement (perhaps in a similar way that Bourke feels pain generates language). Eccleston proposes we look at pain '*the other way round*'. Pain, he says, is fundamentally linked to action, - ie instead of stopping movement or being about being stuck, he argues it actually motivates towards movement. I can accept it motivates action as an attempt to avoid threat, as escape or avoidance, but the very action motivated, as Eccleston himself acknowledges, remains within the same endless cycle which he describes as an incessant loop from which there '*is no escape until the pain is reframed*'. For me this continually repeated '*incessant loop*' suggests blockage to new action or new perspective, placing the reframing of the problem of pain still firmly within a framework of flow and blockage, reminiscent of humoral theory.

Bourke suggests that the sensation of pain was experienced differently in the medieval period, to that experienced in either the more mechanistic industrial age or our contemporary age with its metaphors of invasion and germ theory. Re-reading this though, I wonder if there isn't something instinctual about humoral theory correlating with more non-medical contemporary conceptions of the body. If I look at the images we created during **perceptions of pain** and **face2face**, many of them refer to fluidity or lack of it, to blurred boundaries between the body and the environment around it, to heat, to the blackness of melancholy or the red of blood, so I wonder if there are distinctions not only between historical periods but between the conceptualisations of patients and clinicians at a very fundamental level. My own image of a frozen hand (fig 14 ) references both solidity and flow, blockage and movement; it denotes a solid material bounded by its mould, it connotes liquid which will eventually flow



and seep beyond its boundaries, will change its form, and melt into its environment. It is perhaps not purely the language and metaphors of different historical periods but the language and metaphors of different discourse communities which affect the conception of pain. Patients and clinicians are drawing on entirely different frames of reference and metaphor, one group – patients – draws heavily on what I now consider to be primal metaphors, the language of the senses, and the other – clinicians – draws on scientific metaphors, the language of medicine. Does this offer an example of one way in which the pain cards can help negotiate between the two frameworks, in that they give the clinician a glimpse of the metaphoric world within which the patient is placing their pain?

This theory is supported by linguist Elena Semino's argument that in ***perceptions of pain*** figurative communication is used to '*cross the boundary between members of two discourse communities that have different kinds of 'authority' in relation to pain: personal experience in the case of the participants in the project, and professional expertise in the case of doctors, who were the main audience for the participants' creations*'. (Semino 2013).

### **Christian and religious frameworks**

In the fifteenth and early sixteenth centuries the Church and its value systems began to influence ***perceptions of pain*** in the West and continued to do so for several centuries. A closer fit evolved between disease and "victim" with the growing idea that disease could be appropriate and just punishment (Sontag 1978 p 43). It became moralised, moving from collective punishment towards punishment for individual transgression, with pain '*viewed within a dogma of salvation' a consequence of sin, a means of punishment for religious disobedience.*' (Bourke 2011 b).

Bourke expands, explaining that '*In the early Christian period, it is endurance which gives you status. If pain is something to be endured for the greater good, then you suffer in this world, so you don't suffer in the next.*' (Bourke 2011 b). There became what Bourke terms a '*valorising*' of endurance. To my mind this concept of enduring pain allows social hierarchies to remain the same, and dominant groups to have power over the less dominant, offering them the

possibility of a painless world for eternity in exchange for their acquiescence, with all its consequent pain, suffering and poverty, in this one. An unquiet thought raises its head here - are there vestiges of a similar power dynamic within contemporary parallels of the domination of medical language over lay language in pain discussion? Are patients, while being encouraged to participate in their own treatment, only able to do so if they accept a dominant medical model and framework for their pain?

Historically, there are no visual images for subjective qualities of pain (Cole & Carlin 2011), but there are images depicting the external expression of pain (as in the Laocoon group, marble statue c 80 AD, possibly the earliest example) - see fig 15 and of painful situations or physical pain through attack on the outside of the body, mostly bound up with Christian Iconography and notions of endurance and martyrdom (Hurwitz in Padfield 2003). Images depicting the Martyrdom of St Sebastian for example abound from earlier examples by Donatello and Pollaiuolo, through Holbein to contemporary examples such as Arno Breker (1975) see Figs 16 and 17. There are also a plethora of portrayals of pain, particularly from the eighteenth century, with demons and devils wielding tongs and other sharp instruments '*hacking away at human flesh*' (Hurwitz 2003 in Padfield 2003), for example Gilray's '*Gout*', in the Wellcome Trust Library, London. (see fig 18). Here a devil sits on and clasps a red swollen human foot, breathing fire and sinking its teeth into the skin. Both the martyrdom and devil iconographies depict the points of sharp objects such as arrows, knives, teeth and claws penetrating the flesh. Similarly Richard Tennant Cooper's early twentieth century watercolours of pain frequently depict devils wielding sharp instruments or claws piercing the flesh, for example his *Allegory of Cancer* (Tennant Cooper, early twentieth century, Wellcome Library). See fig 19 employing both knife and claw. Here a claw penetrates the breast of a naked woman, while another naked woman swoops down and pierces the claw with the point of a knife. Semino (2013) observes a consensus equally apparent in the linguistic literature where pain is frequently described in terms of physical damage (Aldrich & Eccleston 2000, de Souza & Frank 2000, Kövecses 2008), seeing the abundance of metaphors of attack for pain in our current vocabulary as a method of exploiting a metaphoric link with pain associated with actual tissue damage. ***Perceptions of Pain*** and ***face2face*** as well as these historic visualisations and verbalisations show a high percentage of metaphors of attack, so is there a deeper more primal category of metaphor emerging which

exists below linguistic overlays and could be perceived as trans-historical, indicating the possibility of a developing trans-cultural iconography for pain?

Compare for example contemporary painter Rosa Sepple's <sup>18</sup> image of a TN attack as a visit by the devil, and Richard Tenant Cooper's watercolour of a man under chloroform attacked by demons with surgical instruments (Wellcome Trust Library) with some of the 18C portrayals of pain as devils and demons in the Wellcome Archives (figs 20 and 21).

Many of the photographs from **face2face** and **perceptions of pain** also depict sufferers being out of control, subservient to another agent with control over their body and emotions, sometimes possessing supernatural or punitive power (Padfield et al, 2010) - see figs 22 and 23.

Vestiges of the notion of pain as punishment I believe have persisted, perhaps through being embedded in our language, *'poena'* in Latin meaning punishment, seeping into current beliefs that pain is somehow deserved, some sort of punishment by an external agent. In discussing the metaphors of cancer Sontag observes the evolution of descriptions of a cancer personality repressing the emotions, ie that the personality comes to be seen as fitting the disease. Conversely TB is represented as a disease of too much emotion (Sontag 1978), Kafka writing in his diary in 1917 *'the infection in your lungs is a symbol, the symbol of an emotional wound whose inflammation is called F(elice)'* (Sontag 1978 p 44). Are there parallels here with the way chronic pain patients are viewed in the medical literature, the "heart-sink patient", those with "poor coping skills" so that they are handed out similarly negative or punishing images of themselves which they then internalise, eventually seeing themselves as responsible for or as deserving of pain? If we look at the phrase one of the participants of the **perceptions of pain** study quoted earlier (Padfield 2003 P 53) *'Pain = Evil : Evil = Darkness : Darkness = Pain'*? - there is an equivalence between pain and evil, suggesting a religious and punitive framework still operating and colouring the experience.

How does this schema of pain as punishment make a person in pain feel? How does it work to intensify the experience? In a fascinating flip, Prof. Tracey is currently doing some work using fMRI's to tap into a religious framework not as a schema of punishment, but as one of external support. Using religious

iconography of the Virgin Mary as a representation of compassion and comfort to those with religious belief, to stimulate modulation of pain experience by triggering the activity of emotional centres of the brain, she has evidenced a direct relationship between emotion and pain intensity (Wiech et al., 2008). When the Catholic Group (as opposed to atheists or agnostics) were shown images of the virgin Mary during painful stimulations, the pain processing on the fMRI appeared to show reduction of pain activity. Wiech et al. hypothesized that *'religious belief helps believers reinterpret the emotional significance of pain, leading to emotional detachment from it'* (Wiech et al. 2008, p 467). Religion or belief here is working to activate the brain's own pain reducing/modifying mechanisms rather than to intensify it. Would this support Bourke's argument that how we perceive pain and the schemas into which we fit it, changes our experience of it? *'There is a vast body of research showing that different cultures and languages possess profoundly different metaphors for pain. To the extent that language affects people's perceptions and cognition, it also affects the actual sensation of hurting'* (Bourke 2011 a). The only way to assess whether it really is possible to create a trans-cultural and trans-historical iconography of pain would be not only to develop my research historically but cross-culturally through working with pain sufferers and clinicians in other continents who operate within different cultural and religious frameworks to me.

### **Pain metaphors in the industrial age**

The metaphors from humoral and religious frameworks contrast acutely with the metaphors emerging during the nineteenth century which reflect images from the industrial revolution, the development of the railways and engineering feats. For example 'railway spine', a syndrome which resulted in paralysis and pain from relatively mild injuries, (a predecessor of post-traumatic stress and the cause of much litigation with the ever expanding railway companies) was a term in common usage (Hodgkiss 2000). Over six thousand miles of railway lines had been built between 1836 and 1852. The railway companies were wealthy organisations and parallel with the expanse of the railways was that of the medico-legal industry and litigation for cases of trauma (Hodgkiss 2000 p129). The metaphors from this age directly reflect the developing industrialisation, the steam train, the engine, machinery, and electricity.

*I have seen the most heroic and stout-hearted men shed tears like a child, when enduring the agony of neuralgia. As in a powerful engine when the director turns some little key, and the monster is at once aroused, and plunges along the pathway, screaming and breathing forth flames in the majesty of his power, so the hero of a hundred battles, if perchance a filament of nerve is compressed, is seized with spasms, and struggles to escape the unendurable agony. (Mott 1862 cited in Bourke 2011a p23).*

Typically, the distressed body was spoken about as if it were a flawed machine, with the physician as a kind of mechanic whose job was to “fix” a faulty mechanism (Bourke 2011a 24). Pain also became an electrical pulse. One patient suffering trigeminal neuralgia put it, “*My pain was caused by a short of two nerves – it’s like electricity. If you put two nerves together and they touch each other, it forms a short and that’s why I got my pain*” (Zborowski 1969, cited in Bourke 2011). This vivid electrical metaphor for trigeminal neuralgia is very close to that of one of the patients I worked with individually in **face2face** who described his pain in exactly these electrical terms:

*Very often I’ve connected the pain to wires. I’ve blown a fuse as well and realized that this is the same problem that I have with my face... A few times I touch my face or skin accidentally and it causes so much pain. I’ve been getting electric shocks all day sometimes...just the face and skin. (**face2face** study code I5).*

When we were photographing his visualisation of his pain, he demonstrated with elastic bands and with wire flexes (see figs 24 and 25). Holding two wires at different distances from each other, first touching then apart, he explained:

*When I’m having a conversation this is what happens, when the wires touch each other like this, is when the pain is most severe. When they are apart, this is when I’m in bed and I don’t feel any pain at all. This one where the wires are closer is when the problem starts, when I get up in the morning and when I try to brush my teeth. Any bit of vibration starts it off. (**face2face** study code I5).*

Itself not far from '*the succession of short, sharp momentary bursts like electric shocks*' Miller records in the *British Medical Journal* in 1968 (Miller p 577).

### **Contemporary pain metaphors of military and germ warfare:**

In the twentieth century disease and pain become characterised more through the military metaphors of aggressive warfare, attack, germ theory. The patient is expected to 'fight' or mount an attack on the disease rather than submit to the will of a punishing deity. Pain is visualised as 'invasive', 'colonising' the body, which is perceived as under attack from external forces.

*The military metaphor in medicine first came into wide use in the 1880's, with the identification of bacteria as agents of disease. Bacteria were said to "invade" or "infiltrate". But talk of siege and war to describe disease now has, with cancer, a striking literalness and authority'.*  
(Sontag 1978 p66).

Metaphors of attack and counter attack not only proliferate descriptions of the experience of cancer and its treatments but of pain. Sufferers were encouraged to '*put on the armour of battle*' to conquer pain (Bourke 2011 p 26).

Many of the images (as discussed earlier) produced during both **perceptions of pain** and **face2face** feature some form of weaponry metaphor whether it be an 'actively stabbing knife', or a red hot sword (see figs 7, 8 and 26). Many of these objects of attack are depicted with their own agency cutting into or attacking powerless flesh or identities. It is probably no accident that the three images most frequently selected in the **perceptions of pain** pilot study all reflect an assault on the body by an outside agent beyond the frame of the photograph (Padfield et al. p 146).

This further supports the probability that some metaphors for pain rather than being culturally or historically specific, actually have a universality, which links them to other historic and cultural contexts. An attempt to create or co-create a visual language for pain could be seen as an attempt to look underneath the metaphors of discrete historical periods and identify a small number of what might be called universal visual metaphors and/or pain icons.

How might a construct of the body influenced by humoral theory, of movement and blocked movement, and one influenced by invasion and germ theory affect our experiences of pain differently? Bourke argues that the '*anatomy of solid parts*' (characteristic of later periods) as opposed to humoral metaphors (of the medieval ages), alters how pain is experienced, affecting the sensation as well as the meaning (Bourke 2011 a). However is there room within this argument for a messiness, for acknowledgement that it might not scan quite so neatly? There might be a retention for those in pain of very early, primal metaphors. Even Bourke concedes that many metaphors used '*have remained constant over the past two centuries*' (Bourke 2011a p 11). It is possible to conclude there are a few primal metaphors which can and do cross cultural and historical boundaries.

### **LITERARY METAPHORS FOR PAIN:**

Poetry like the image works polysemically, it creates spaces for further and multiple meanings which go beyond the sum of the individual words, filling the spaces between them. For this reason it is with poetry and figurative language, (often, as Biro suggests, cathectesis), that writers have attempted to capture the elusivity of pain.

Virginia Woolf contradicts her own ubiquitously quoted observation, '*let a sufferer try to describe a pain in his head and language at once runs dry*' (Woolf 1930 p194) when she concludes that because of the: '*poverty of the language of pain*' ... *[a person with pain] is forced to coin words himself, and taking his pain in one hand, and a lump of pure sound in the other ... so to crush them together that a brand new word in the end drops out,*' (Woolf 1930) so creating a new and graphic image for pain.

There is an interesting intersect between language and image within literary metaphors, the former producing virtual reflections of the latter in the mind of the reader; the literary metaphor does not exist without its visual shadow. Similar perhaps to Bourke's belief that pain generates rather than destroys language, David Biro promotes an idea that literary pain metaphors create an environment in which pain can be processed, that they do this by expanding time and space, slowing it down, in direct contrast to the rapid and reductive environment pain often takes place in - the hospital - where there is little time for reflection.

Metaphors for pain have a function. To understand something less tangible, less familiar to us we need the spaces literature and images supply to engage with it, wrestle with it and allow it the necessary time to unravel and reveal its meanings. Using Stephen Dedalus from Joyce's *Ulysses* as an example, Biro says of literature's reliance on metaphor for communicating pain:

*For Stephen the facts are as follows: inside him are sensations he doesn't understand and cannot speak about; outside are things he does understand and can speak about. And because this situation is intolerable, he needs to alter it. He does so by mixing up categories, by taking from the things he does understand in order to illuminate the things he does not. He does so, that is, by metaphor, one of the most powerful means of world-making at our disposal. Metaphor exchanges absence for presence, darkness for light, and silence for language. (Biro 2010 p68).*

The way in which Dedalus is described as objectifying his painful symptoms by projecting them onto objects such as the bathroom sink, and turning them into objects outside himself has parallels with the methods participants in both **perceptions of pain** and **face2face** used to convey their sensations. For example the very poetic description used by one of the sufferers I worked with at St Thomas' quoted below uses exactly this mechanism:

*It is just in agony by the look of it. I caught it on a bad day. I didn't have a very good day that day. The head is down, it just seems as though it has ended its life, but what it will do this year is it will shoot back up again. The roots are strong. It varies with me. This one will come up again.*

Here she moves seamlessly between describing the sunflowers in her garden (outside her) depicted in the photograph she had brought with her to describing her own emotions (inside her). Both the Input patient quoted above and Joyce's Dedalus employ Aristotelian 'substitution' in order to convey an experience which resists available language, substituting objects in the external and sharable world for the more elusive qualities of their interior worlds.



When language is used to convey physical suffering, it either resorts to metaphor or, quite commonly, recedes into silence; the '*blank*'<sup>20</sup> of Dickenson's poem, the '*white silence*'<sup>21</sup> of London's (1991), or its counterpart, the primal scream (which cannot be broken down into signifying words), '*I began a scream that lasted intermittently during the whole time of the incident - & I almost marvel that it rings not in my Ears still! So excruciating was the agony.*' (Burney in Hemlow (ed) 1986 pp 127-41).

### **Metaphors of sharpness: ice, needles, claws, spears**

*The crawling glaciers pierce me with the spears  
Of their moon-freezing crystals, the bright chains  
Eat with their burning cold into my bones.*

(Shelley, *Prometheus Unbound*)

Pain and suffering are commonly depicted as happening at the hands or teeth of animals or armoured assailants, as submissive to a cruel external agent. We can identify with a gnashing of teeth, with the sharpness of their points.

In *The Stethoscope* Dannie Abse writes of the '*night cries ... moonlight sonatas on a needle*', and in my life as a doll, Elizabeth Kirschner writes:

*I jerked  
about like a marionette with  
tangled strings—slash of claws, teeth  
sinking in to rip the flesh off  
my wooden bones.*

We know and can see the sharp point of a needle, knife or claw. Of his pain from syphilis, Daudet wrote in the notebooks published by his widow after his death, '*Rats gnawing at the toes with very sharp teeth*' (Daudet 1930 p 21). Can we imagine these sinking into our flesh – do many of us corporeally know this sensation? In W H Auden's words:

*Who when healthy can become a foot?  
Even a scratch we can't recall when cured.*

(Auden, *Surgical Ward*)

Are words enough to embody the sensation of pain or do we additionally need the materiality, the shapes, colours and forms of images?

### **Multimodal metaphors for pain**

When linguist Elena Semino (2013) analysed the metaphors in both the images and testimonies published in *perceptions of pain*, she described the testimonies accompanying the photographs “*as too lengthy and detailed to be described as captions*”, concluding that ‘*the artworks can therefore be seen as instances of a hybrid, multimodal genre that came about in the process of collaboration between Padfield and the participants.*’ (Semino 2013 p 281). She uses Forceville’s definition to describe what she means by ‘multimodal’:

*As a first approximation, I will define multimodal metaphors as metaphors in which target, source, and/or mappable features are represented or suggested by at least two different sign systems (one of which may be language) or modes of perception.*  
(Forceville, 2008 p 463).

As many of the metaphors in both *face2face* and *perceptions of pain* appear to live at the intersect between word and image, this might be a useful way to define their dual functioning. The linguistic metaphors emerging during both projects have been shaped by a visual process, reminding us of the corporeality of pain experience, through the materiality of the photographs produced. There is both interplay and space between language and image here. The necessity of reaching across such a space shapes the emerging metaphors utilising the potency of both modes to arrive at something stronger than either would accomplish on their own.

Observing that the articulation of private experience through an artistic process appeared to result in linguistic patterns characteristic of autobiographical writing,

for example 'a high frequency of first-person pronouns, of references to mental states and processes (e.g. idea, feel, believe), and of evaluative expressions (e.g. important, terrible, stigma)' (Semino 2013, p282), Semino concludes that the 'representation of each sufferer's experience is achieved via the multimodal interaction between words and images'. (ibid p 282).

Before looking at visual metaphors on their own, I would like to spend a little longer exploring Semino's analysis of the metaphors as '*multimodal*'. See fig 27.

Speaking of an image of medication thrown across an ever growing rubbish dump in ***Perceptions of Pain***, Semino describes it as demonstrating how 'each verbal testimony forms a multimodal or 'composite' text with the group of photographs it accompanies, so that the use of metaphor and metonymy needs to be discussed in the light of the interaction between the visual and verbal components in each case' (Semino 2013 p280). Semino asserts that Conceptual Metaphor Theory (CMT) provides a suitable theoretical background for this kind of analysis, because it views metaphor and metonymy as conceptual phenomena that can be realized via different semiotic systems. In the example above, the same RUBBISH TIP metaphor is exploited both visually and verbally,

Semino quotes the co-creator of the photograph, Rachel Brooks:

*'I see a huge rubbish tip that has mounds of rubbish in it (1). It feels to me that there comes a point in my pain where I feel that things are under control and running along fairly smoothly, when suddenly another load of rubbish is poured onto the site and I am back to square one (2). It can be other people's rubbish, it can be a change of medication, it can be anything (3). I can never be truly in control or get the rubbish level and smooth, because always something comes along and makes it mountainous again (4). It is about absolute chaos and the feeling that people come along once a day or a week and just dump more rubbish on the tip (5). (Brooks, in Padfield, 2003 p 283)*

I have left Semino's underlining marks in as they relate to her analysis. Semino observes:

*As our underlining shows, the extract has a very high density of figurative expressions. According to our analysis, 48 out of 123 words are linguistic metaphors, amounting to 39 per cent of the total. This density can be described as very high as compared with the findings of other studies (e.g. Steen et al. 2010). ... This confirms the importance of metaphor and metonymy in the expression of pain experiences, and the freedom that participants in the project enjoyed to develop in detail their own metaphors and metonymies (Semino 2013 283).*

I would add not only that there was a freedom to develop their own metaphors but that it is significant that pain is depicted very materially here, additionally the way the medication is thrown across the images is suggestive of activity rather than passivity. These qualities serve to emphasise the sensation of being out of control, to highlight the chaos and fluctuations experienced by the sufferer which prevent life from feeling solid or stable. I would argue this is achieved by a combination of image and word, and their interplay adds potency to both. Issues of interpretation necessarily arise when viewing images, but the addition of text or speech re-directs meaning to that which the sufferer wishes to communicate rather than that which the viewer wishes to see. It is an important part of the collaborative process.

Semino (2013) identifies that we can assume a high degree of inter-subjective agreement on the precise quality of pain sensation conveyed by each descriptor (Semino 2013 p 272) as many of the terms used describe experiences few of us have experienced directly, such as boring, stabbing, lacerating and searing. She concludes, therefore, that there is a more complex and broader significance to individual pain than mere physical puncturing and its terms, and its significance is different for all of us, perhaps, I would add, different for each of us in different contexts and at different points of our lives. Her comments also raise important issues around the significance of individual pain. The question is raised 'can words on their own render these materially or do we need a catharsis between word and image with which to embody and so share them?' I am beginning to feel that we do and that perhaps neither image nor word on their own has the ability to capture individual pain experience or elucidate its significance.

The following testimony from **face2face**, recorded during the image-making process, is a good example of how the metaphors are jointly shaped by word, image and virtual image (ie in the imagination) and how physical objects act to generate further symbolic as well as metaphoric meaning. The words foreground the photographic process in the making of meaning. Neither the language nor the images on themselves would have the same effect; both are mutually generative (see fig 28).

*... this ice-pick above your head,... you are totally unaware of all this sort of stuff and then it's there over your head, so I think that expresses it... Its almost like being a war photographer, you need to convey to other people what's going on, but doing it seems incredibly intrusive and almost sort of cold hearted; ... Yes, that's the sort of fear. That's how I feel at the moment, this sort of fear of when it's going to drop, ... when this ice pick is going to (clicks fingers) ... It's the drill, it's the drill... it really needs to be pointing more, but this one does, here the shadow does go straight into my head. ... I suppose in a way the rocks are sort of symbolic of a sort of difficulty, difficult terrain; they represent a problem. The rocks, have become symbolic haven't they .... that really has a sort of lonely despair. ... (**Face2face** participant study no 14).*

Through metaphor the objects of agency are described as endowed both with the ability to inflict harm on the body and with the emotions that harm might produce. I find this fascinating as it confers a duality on the instruments of pain, as well as yet again turning to descriptions of injury to express it. In many of the metaphors I found in literature the body was absent, although it was the target for the pain. In the transcripts from workshops during the **face2face** project the metaphors interact directly with the body; the body is extremely present whether or not it is literally depicted and although the words in this testament do not necessarily have the concision of poetry - as they were spoken - what they do very effectively, is position the physical presence of the person in pain centrally within the metaphor. I believe that had we been talking without referring to the images, the language quoted above would have been much thinner. What is emphasised is the physicality of the person in the room; the person with pain actually selecting the objects, the images, pointing out the ice axes and shadows. Theirs is not an abstract concept, theirs is a physical reality which is living and breathing in that room as we co-create the photographs. Theirs is a

body which is saying “*I am here. I hurt*”. Joanna Bourke suggests that metaphors are not only attempts to describe sensation of the less familiar through the familiar, but that they also contain clues to more complex, unspoken meaning as well. “*They are important indications of the relationship of a person to her pain and of the kind of pain she feels*” (Bourke 2011a). I think the addition of an aesthetic to a linguistic space for the metaphors to operate in brings this relationship to the fore.

### **Language as an extension of the self**

David Biro echoes explains: ‘*because language provides a means of self-extension – a means of moving beyond the self and toward others – it offers a way out of the crisis. But pain, in its adamant resistance to language, appears to obstruct this escape route when it is most desperately needed*’ (Biro 2010 p 107). Poet after poet describes the powerlessness of language in the face of intense pain: ‘*Wordless, hell was wordless and I, was in it*. (Elizabeth Kirchner: from IV. O Healing go Deep)

In pain, more than at almost any other time, we long to cross the space between ourselves and others, to communicate in some way the completely present overwhelming sensation which is forming a barrier between ourselves and others, and the self we would like to be. Pain calls for empathy but it does not provide the language with which to find it nor do we always feel entitled to ask for it. In his introduction to Daudet’s *In the Land of Pain* (1930 tr 2002), Julian Barnes draws attention to the paradoxes of long-term pain. Barnes quotes Daudet saying to his last secretary Andre Ebner, “*suffering is nothing ... It’s all a matter of preventing those you love from suffering*’. Barnes sees this as exemplifying the irony of the way you can be on the one hand surrounded by those you love and unwilling to inflict pain on them by describing your own pain, so depriving yourself of the comfort you long for, while at the same time your illness, which is producing ever new symptoms all the time, has become banal and boring to them. Daudet describes how pain drives out language and it is only after it has subsided slightly, that words can come “*only when everything is over, when things have calmed down. They refer only to memory, and are either powerless or untruthful*” (Daudet 1<sup>st</sup> pub 1930 tr Barnes 2002 ). <sup>23</sup>

When Alicia Ostriker<sup>24</sup> claims in '*Masechtomy*' that '*a breast surgeon minces something other than language*', she is pointing not only to the corporeality of pain and the limitations of the surgeon but to the limitations of language itself. I would claim that a combination of literary and visual metaphor allow us to get closer to finding a viable form with which to convey the individual lived experience of pain from one body to another.

## VISUAL METAPHORS

### Perceiving the body via visual metaphor

Barbara Stafford has written extensively on the art object in relation to analogy and visual metaphor as means' of understanding the human body in the context of neuroscience and consciousness theory (Stafford 1993, 1999, 2007). She emphasises the instinctual as opposed to logical nature of the leap which the visual metaphor makes from the known to the unknown, claiming that '*the body cannot be 'read'*, it is '*perceived, visually, sensually.*' Could the same be said of the photograph, the visual metaphor standing in for the body in pain? We do not just 'read' it; we perceive it visually and sensually. If we only 'read' it, we omit the most insistent aspect of the pain experience itself, - that it is experienced with and through the body. Its representation demands a material and corporeal element. It cannot be communicated via language alone. This last section of chapter one seeks to understand what it is that visual metaphor adds to linguistic metaphor.

Speaking of the ***perceptions of pain*** images, Canadian occupational therapist and academic Cary Brown wrote:

*Perhaps when words fail, as they often do for people with pain, images can be used to give pain a presence accessible to others.* (Brown 2008).

Artist Susan Aldworth takes the integration of metaphor and materiality to its limits when she uses brain tissue to create prints of *passing thoughts*, 2013.<sup>25</sup> We are aware that it is the same tissue we are witnessing with, which we are using in ourselves, to perceive the thoughts of another. The materiality of the image brings a significance which would be entirely omitted if these were purely

linguistic philosophical musings. In ***perceptions of pain*** and ***face2face*** it could be argued that the experience of other people's pain is also being used as a material <sup>26</sup> with which to construct visual metaphors and make them accessible to others - that their impact could not be possible without their materiality. How does this materiality make itself felt?

### **Pain as a surreal experience**

Pain is not logical. Just as the surrealists found visual metaphors a means of expressing the unanswerable 'questions of existence' so too do those in pain, maybe that is why so many of the images created during both ***perceptions of pain*** and ***face2face*** have a surreal aesthetic. In surrealist work there is an element of surprise, a bringing together of objects not usually juxtaposed which creates new meaning and forces us to review those familiar objects. It maybe that it is not only metaphor we reach towards in trying to find expression for pain but surreality. We bring together visual objects we are familiar with but not necessarily familiar with them in that context, that relationship or that arrangement.

Artist Rosemary Feit Convey asserts that:

*Aesthetic experiences move us beyond our logical frame of reference, combining psychological symbols and cultural references to form a language that resonates in each viewers' subconscious. This is not knowledge that leads to a neat and easy solution; instead, it raises the most fundamental questions of existence. (Feit Covey 2011, p123).*

In his first *Manifesto of Surrealism*, André Breton wrote:

*Surrealism is based on the belief in the superior reality of certain forms of previously neglected associations, in the omnipotence of dream, in the disinterested play of thought ... I believe in the future resolution of these two states, dream and reality, which are seemingly so contradictory, into a kind of absolute reality, a surreality [sur = "on", "above" in French], if one may so speak. (Breton 1924).*



Surrealist approaches allow images to resonate polysemically, allow new meaning to be generated from unfamiliar use of familiar objects and in this way complement the way that metaphor works within language. What potential can be unleashed by the combination of surrealism and visual metaphor?

It is difficult to say '*I feel like a man trapped in cement*', it is difficult to say '*I feel like a cement mixer swallowing cement*', it is difficult to say '*I feel like a shadow sandwich*' particularly in a medical context. It is possible to say it using visual metaphor and it is possible to suggest the overlays of meaning and personal significance through visual metaphor which resist capture in language alone (see figs 5, 6, 12 and 29).

The fogginess, the smothered indistinct profile, the claustrophobia, the decomposing nature of the bread, the lack of visible mouth and thus lack of voice with which to speak are not legible within the word "*shadow sandwich*"; but they are within the visual image, able not only to activate our personal and cultural associations but to act on our bodily senses, increasing our sensorial understanding of what it means to have facial pain.

### **Materiality of visual metaphors**

Similarly, I believe the photograph below elicits a physical reaction in us which the words "*knife through a strawberry*" on their own might not. The visual metaphor takes it beyond being merely an idea, or merely personal insisting that the viewer responds with their body, that they see it with their eyes, and process it with their brain so it becomes a sensorial as well as intellectual experience. As the viewer or witness touches and handles the image, his or her nervous system is responding, sensations of touch, not so dissimilar to pain sensations, are being processed by their brains. He or she cannot separate him or herself from the image as existing in the world of the other, it has entered his or her own world of sensation (see fig 30).

The verbal metaphor replicates the metaphors of weaponry discussed earlier, with echoes of Daudet's "*knife slicing through a banana*" (Daudet 1930) of Elizabeth Ross Taylor's '*knife-edge of light, pain's night-light*'<sup>27</sup> and many other knife metaphors. However in addition to these poignant phrases, the image has a viscosity words cannot quite conjure up. The strawberry is organic, it has

flesh and a surface skin which we relate to our own. It is blood red, as is its juice. We almost wince when we “feel” the knife cutting through it, and identify with the ‘tear’ running down its side. The shape of the strawberry is almost that of a heart. The visual metaphor can resonate ambiguously allowing for duality and polysemy. The knife is both a metaphor for pain and a literal signifier of the surgeon’s knife, simultaneously an agent of pain and a healer of pain.

This isn’t only my perspective but that of others too. For example of the image below, Semino says:

*Frances’s verbal description ... makes fully explicit the figurative function of the daggers, as well as the fact that their redness is meant to represent the perception of (metaphorical) heat. In the visual image, however, the contrast between the red objects and the dark background may have a greater potential for sensorial and emotive impact than is the case with the verbal description. (Semino 2013 p288).*

Of the black and white photographs of a claw and cement and spiders crawling up the arm underneath the skin, see figs 31 and 32, Semino writes:

*These photographs are potentially more emotive and disturbing than Rob’s accompanying text, especially due to the size and sharpness of the claws in the first two images, and the shape and density of the ants in the latter two. (Semino 2013 p 290).*

She goes on to conclude: ‘*These images arguably convey more directly than any verbal description the sensations experienced by sufferers*’ (Semino 2013 p291)

Time and time again clinicians have observed that they could see and feel the patient’s experience more clearly looking at the images than listening to their verbal descriptions. Responding to the images in the **perceptions of pain** exhibition when first shown at the Crawford Gallery in London, the reviewer from the *BMJ* (11 May 2002) confessed:

*Viewing the pictures was a numbing and uncomfortable experience for me. Perhaps that is a typical doctor’s reaction ... faced with something*

*too hard to understand and to which I felt I had no answer, I wanted to shut off. But somehow these pictures wouldn't let me.*

I would argue that visual images are able to add on to metaphor the layers necessary to capture the surreal nature, the multidimensionality of pain, and that verbal metaphor alone does not capture such complexity. There is an imaginative space created through metaphor, but that space does not invite the listener/viewer in as fully as aesthetic spaces do.

### **Visual metaphor: engagement and interpretation**

When we curated the **mask : mirror : membrane** exhibition resulting from the **face2face** project, we did so in a way that meant viewers would experience the large photographs as they entered the gallery, unaccompanied by text. The aim was that they would be free to project their own interpretations and associations onto them and then move to the back of the space where the smaller images depicting the 'patient journeys' were accompanied by patient testimonies fixing them more in their particular narratives (see fig 33).

For some viewers this was problematic: they felt much of the power came from the personal narrative and they wanted it from the outset; but for others such as photographer and therapist Rosy Martin <sup>27</sup>, it allowed a space for the audience: *'I like the way it's hung, I like the way I can appreciate the images and then read the story.'* She went on to emphasize the importance of a space for the viewer:

*To me this is not a traditional portrait at all, it is story telling through metaphor, through association, and there is a lot of openness offered so in that sense the work is very mediated. It gives me the space to enter it, as it isn't overly determined. It has to be open enough to speak to an audience.*

What Rosie Martin points to I think is the materiality of the art object, the aesthetic space as a materialised metaphor as well as a signifier. I think it works best when, as Martin observes, the meanings within the metaphor are not overly determined or limited to the specific narrative of their co-creator. They need to open up a space for meaning to be discovered and negotiated.

## The Pain Cards as visual metaphors with materiality

With the images as pain cards, I hoped that again their reading could be open, while still providing a shared reference point from which doctors and patients could discuss individual meanings of pain. The relevance of revealing patients' metaphors is endorsed by Ana-Maria Rizzuto's paper '*metaphors of a bodily mind*' (Rizzuto 1999), where she asserts metaphor's potential to '*make accessible to them, and to the analyst, experiences that cannot otherwise be put into words*'. I would argue that with the pain cards, there are additional mechanisms such as their materiality and aesthetics complementing the metaphoric meaning connoted, providing unique access to what '*cannot otherwise be put into words*'. The photograph becomes the body, combining subjectivity with visible and tangible physical form - the photograph as a visual metaphor moves us closer to a conception of an embodied subjectivity such as Elizabeth Grosz proposed (1994). This is particularly relevant to the pain experience; pain is experienced in and via the body, it is processed in the brain, the one influencing the other, both forming part of a continually evolving plastic system of perception. The International Association for the Study of Pain (IASP) defines pain as both a sensory and emotional experience (see page nine for full definition). The colour, shape, texture and form of the art object acts on our bodies as well as on our perception; our senses are drawn into the metaphoric and imaginative space. We don't just conceptualise its meaning, we experience its meaning. This brings us much closer to an understanding the lived experience of pain.

Academics (historian and theologian respectively) Cole and Carlin wrote a chapter analysing the images from ***perceptions of pain*** entitled '*Maldynia as Muse: A Recent Experiment in the Visual Arts and Medical Humanities*' (2011) in a book on chronic pain (Giordano 2011). In it they describe images as able to '*span the seemingly unbridgeable gap between the one who suffers pain and the one who hears about pain*' (Cole & Carlin 2011 p 104). It is the materiality of the image it is suggested which in some way facilitates empathy. They describe the photographs as '*metaphorical self-portraits*' – which I would agree with – framing these self-portraits as material objects (ibid p 114). Cole & Carlin reference James Elkins' argument that '*every picture is a picture of the body ... this is to say that we see bodies even where there are none*' (Elkins 1999), highlighting the corporeality of images; the way that the images as photographic

objects hold feelings and memories of the body. Focusing on both objects within the images and the photographic objects themselves as containers of feeling and experience, Cole and Carlin also reference the work of psychoanalyst Christopher Bollas, arguing that transformational psychoanalysis, of which he is an exponent, might be a useful way of exploring the images, and their ability to be cathartic agents in the release of feelings and experience projected onto them (Cole & Carlin 2011 p 118). In *Being a Character: Psychoanalysis and Self Experience*, Bollas argues ‘we consecrate the world with our own subjectivity’ (1992 p 3) describing how we select and use objects, projecting our inner worlds onto objects in the external world. Speaking of object relations theory Bollas states:

*It is rather surprising that in “object relation theory” very little thought is really given to the distinct structure of the object which is usually seen as a container of the individual’s projections. Certainly objects bear us.<sup>28</sup> But ironically enough, it is precisely because they hold our projections that the structural feature of any one object becomes even more important, because we also put (ourselves) into a container that upon re-experiencing will process us according to its natural integrity. (Bollas 1992 pp 4-5)*

This statement highlights the relevance of considering the material and aesthetic qualities of images, the forms and structures which exist in addition to their metaphoric properties, supporting the argument that it is such visual metaphors which are able to come closer than other metaphoric forms to the embodied experience of pain. Bollas’ theories suggest that transformation can be effected for a person in pain through recognition of the experience these forms hold for them. They also raise the question, can transformation equally be experienced in the viewer through bodily as well as intellectual awareness of their significance?

Looking at her image (fig 69) a participant in *perceptions of pain* said:

*... when I first saw the images that Deborah and I produced together I felt a shiver of recognition mixed with feelings of anger and sadness. But for the first time I was able to point at something and say ‘that’s my pain. (Sinfield in Padfield 2003 p33).*

It is this emotional and physical response to visual metaphors which makes them so apposite for capturing the pain experience and so effective an agent for sharing it with others. Although I disagree with some of the statements made by anthropologist Alfred Gell, such as his denial that objects can be signs with 'meanings' (Gell 1998 p 6), what I value in his work is his concern with the actual qualities and characteristics of the art object, and its potential to be a relational object with its own agency. *'In place of symbolic communication, I place all the emphasis on agency, intention, causation, result and transformation'* (Gell 1988 p6).<sup>29</sup>

I think the visual metaphors created during **face2face** and **Perceptions of Pain** do have symbolic meaning, which could be analysed usefully through a semiotic or psychoanalytic approach. However, as a means of understanding other ways in which the visual metaphor might be operating, I find Gell's approach illuminating. The visual metaphors we created not only involved the senses and the body through the eyes in the act of perceiving them, but in the case of the pain cards, involved the senses and the body through the hands of those passing them back and forth. The image was not only acting as a shared reference point, but a shared metaphor within a physical exchange. As a metaphoric portrait of that patient it became, in Gell's words, an example of: *'personhood spread around in time and space'* (Gell 1998 p 223) within the consulting room. The material qualities the visual metaphor possesses and the ways we respond to that in time and space, not only elicit affect but effect change and transformation within the relationship. Visual metaphors become relational. They have agency.

The sharing of the metaphor corporeally as well as intellectually reduces the isolation of sufferers. Photographer Jo Spence speaks of the process of sharing photographs as a social and a transformative process: *'Photography transforms a living scene into a piece of two dimensional graphic art – a representation of the moment but drained of all life, sound and smell – an abstraction, a fragment of the moment but unlike our ephemeral memory it can be shared. It is a physical object we can hold it, pass round, discuss and archive for posterity. So I see Photography as a magical process'* (Spence 1982 cited in Dennett 2011 p 235). Both those who have expressed their pain through the act of co-creating the images and those who recognise and respond to them are involved in the act of 'sharing' an experience beyond words. Following an analysis of the

**perceptions of pain** project David Biro writes: '*Expression inevitably leads to knowledge and community, and it may also work like medicine to lessen our pain.*' (Biro 2010 p180).

Communication, as Biro has indicated, comes from '*communicare*' in Latin meaning to '*share*'. The materiality of the visual metaphor allows a different type of sharing to take place. I would add that the ambiguity of the visual metaphor also encourages a negotiation, because, as Barbara Stafford has pointed out, the links between the known and the unknown within the visual metaphor are likely to be instinctual. They will be based on our individual experience, narrative and embodied experience of the world, they will therefore be different for each one of us. The ambiguity of the visual metaphor allows for polysemy rather than a 'correct' or 'appropriate' single reading, (in contrast to medicine's 'appropriate' or 'inappropriate' pain level or coping behaviour) and this is what I believe makes it an exciting means for expanding dialogue in the consulting room and expanding our tolerance of another's perspective.

In a chapter entitled *The Voice of Pain* in a book on the embodied self, cerebral palsy sufferer and academic, Minae Inahara, reinforces this point, advocating the value of the plurality of readings which images permit and the consequent benefits for pain sufferers trying to articulate the inarticulable:

*In looking at some of the images, which Padfield offers, certain things must be borne in mind. Although I say certain things about the image, what I say is not meant to be a substitute for the image itself. For this is exactly what the discussion of Kristeva has suggested is not possible. My words and sometimes the words of those who have been involved in the construction of the images may help draw our attention to certain aspects of the image, but the image does additional work. It breaks the silence of the pain sufferer in a distinctive way. Moreover, a way that is open to a plurality of readings* (Inahara 2013 p 187).

In the same book Inahara cites neuroscientist, Jonathan Cole, who argues that an understanding of Wittgenstein's work <sup>30</sup> is essential for overcoming the dichotomy between the perspective of medical knowledge and that of first-person experience or subjectivity:

*In clinical medicine, how we interpret another's pain, or any experience, is obviously hugely important and yet often we are not good at it ... People often lack the words to explain their inner experience, and we lack a good framework on which to relate their external physical loss to their internal psychological state. (Cole 2007 p 60)*

Cole highlights differences in interpretation as fundamental to the chasm between patient and clinician understanding. What the images in **perceptions of pain** and **face2face** aim to do is to encourage a negotiated dialogue, able to reveal the interpretation both patient and clinician are placing on pain and shift both towards a new collaborative construction of that particular pain, its significance in the patient's world and shared discussion of future management choices in the external world which patients are happy to adhere to. How an image might do this is the subject of the next chapter.



# MIRROR

*Art reflects society back to itself better than society can otherwise see*  
(Shapiro 2009, p.2).

Photographic art, like the mirror, allow us to see ourselves, slowing down time to allow reflection. It is the face that historically has claimed to 'mirror' the soul. Like so many participants, Respondent T30, when asked of the role of the face, replied: *a mirror of the soul*. Even Wittgenstein writes: '*... if someone has a pain in his hand, then the hand does not say so (unless it writes it) and one does not comfort the hand, but the sufferer: one looks into his face ... (Wittgenstein (1958, Philosophical Investigations. p98 – 101).*

It is a notion challenged by contemporary portrait photography but also by some of those with facial pain. For them pain is more easily communicated by being projected into objects, including the photographic plate. Academic and physician David Biro defines the mirror metaphor as one of three main types to which pain sufferers turn. '*A second strategy occurs when pain is projected onto other objects ... Projection metaphors enable sufferers to validate and better understand their pain.*' (Biro 2010 p 16).

We need to problematise the mirror or projection metaphor, we need to question what it is we see when we look at the face of another, is it them, or ourselves, - their pain or ours? We need to employ the polysemy of photographs to help us understand experience alien to us, to tolerate complexity and ambiguity, and the pain of not knowing, of not having an answer.

Referencing Scarry (1985) Koppers describes how '*Pain flees outward toward imagination, from the dense matter of bodies to perception itself, ..*' (Koppers 2007, p76). Can we employ creativity, and the photographic plate, itself a mirror, to reflect to us the ways in which we, like all substances, have 'relations which express all the others', making us 'perpetual living mirrors of the universe.' (Stafford, 2001, p126 referencing Leibniz).



Fig. 34

## CHAPTER 2: THE PHOTOGRAPHIC PERSPECTIVE

### INTRODUCTION

#### Why use photography?

#### Tagg and the specificities of the photographic medium

*There is a dark room. A shutter opens. The room is flooded with light that threatens to bleach the interior white. Instead, it leaves a carefully patterned tracery on one wall, because, in entering the room in the only way it can, this light has been tempered, corralled, and organized, transposed from a flaring effulgence into a predictable series of rays, gathered and strung like wires or threads from the single aperture that opens to the outside. Across the darkness, the fall of light is thus graphed by the grid built into the window of the converging lens and the geometry of the walls whose rectangulate architecture orchestrates the relation of the central opening to the focal plane and to the frame marked by the boundaries of that plane's flat surface. This carefully constructed room has an old name. It is a camera. (Tagg 2009 p1).*

Tagg's description of the house as a metaphor for the camera, a meeting point of exterior light and interior darkness into which it penetrates and onto whose walls it leaves traces of events beyond itself, is a useful one with which to begin exploring the specificities of photography, which make it a particularly apposite medium for this project.

## **Body and camera as space where darkness and light, interiority and exteriority meet**

The house, a contained space where light enters through constructed apertures, is comparable to the interior of the body bounding the self, entered only via its natural orifices or those artificially constructed by medicine or injury, a metaphor for the psychological space of the mind or the photographic frame delineating and capturing one perspective, one moment in a flux continuing beyond and external to its frame. To have visibility within a psychological space or within the physical space of the body, to produce a photograph at all, there has to be light, a space through which it travels and a surface onto which that light falls, resulting in exchange or 'alchemy'. Tagg goes on to define the room as training light, *'graphing it - quite literally, photo-graphing, subjecting light to the punctual rule of the room's inbuilt geometrical law. The camera is, then, a place to isolate and discipline light, like a room in Jeremy Bentham's Panopticon.'* (Tagg 2009 p1) and, like that room in the Panopticon, *'the cell of the camera has its utility both as a training machine and as a device for producing and preserving text'* (Tagg 2009 p1). Here photography is associated with a less safe space, one of surveillance. In one metaphor, photography's dual functions as both containing space, a meeting between light and darkness, a membrane between internal and external worlds and a more dangerous function as a space of surveillance are brought together. Both are intrinsic to the way photography functions. Foucault, in describing the depths of the interior of the body and its conception at the end of the eighteenth century as corporal opacity, also describes its interior darkness and *'the slowness of the gaze that passes over them, around them, and gradually into them, bringing them nothing more than its own light'* (Foucault, 1963 p xiii). Is he also using a metaphor for the body which could be conceived of as parallel to the space of the camera, lit by the light of the gaze?

## **The house of pain**

In a recent article in the British Pain Society's Newsletter, Social Anthropologist and psychotherapist Kate Maguire identifies the house as a metaphor frequently used by pain sufferers, *'Most of my clients, who are either survivors of torture or who have come back from working in conflict zones with medecins sans*

*frontieres (MSF), use a lot of metaphors. One of these is 'entering a house of pain' – like approaching a haunted house.'* (Maguire 2012 p116 )

In '*Man with a pain*' Susan Sontag also uses the metaphor of the house to represent pain.

*'The pain is a house, with many rooms. Or, he is a house in which the pain lives. Or, they both live in the house together.'* (Sontag 1964 p73).

Pain is depicted as a contained or containing space, a private defended space, difficult for the external world to enter. It is perhaps this meeting point of dark and light, of internal and external which is as pivotal to pain as it is to photography and on which perhaps this thesis unknowingly rests. In examining a space between word and image, between clinician and patient perspectives, medicine and art, am I also exploring the function of liminal space, and what role images can play in helping us understand or navigate it.

### **The wound: liminality between interiority and exteriority**

In terms of the body, the wound might be seen as a significant liminal site for the meeting of interior and exterior worlds, of what is visible and what is normally invisible. Community artist and academic, Petra Kuppers, describes the scar as:

*a locus of memory, of bodily change. Like skin, a scar mediates between the outside and the inside, but it also materially produces, changes, and overwrites its site.* (Kuppers 2007 p 1).

The photograph could also be conceived of as a wound, or its consequence, the scar. A wound punctures what we expect to see, punctures the safe boundaries of self and other, drawing on individual and cultural memory and association, signifying beyond its self.

Roland Barthes' captures this beautifully in his conception of the photograph as a wound and his description of the *punctum*. His writing is a good place to begin looking at the indexical nature of the photograph and the potential value of a semiotic analysis of the photographs produced during **face2face**.

## REPRESENTATION:

### Barthes and the photograph as indexical construct

Of the photograph Barthes writes: '*I wanted to explore it not as a question (a theme) but as a wound: I see, I feel, hence I notice, I observe, and I think*' (Barthes 1993 p 21). He identifies the ability of photographs to reflect beyond the limits of their frame, to look beneath what is apparent. The photograph is not an exact 'copy' a literal 'representation' it is a construct, it has an author, it involves selection and framing, so Barthes moves away from his initial position that a photograph simply *denotes*, to accepting that it can also *connote*. He describes the '*punctum*' when present in a photograph as able to elicit affect, drawing again on the metaphor of the wound:

*The second element will break or punctuate the studium. ... A Latin word exists to designate this wound, this prick, this mark made by a pointed instrument: ... This second element which will disturb the studium I shall therefore call punctum; for punctum is also: sting, speck, cut, little hole – and also a cast of the dice. A photograph's punctum is that accident which pricks me (but also bruises me, is poignant to me) (Barthes 1993 pp 26 – 27).*

Although in the photographs produced during **face2face** the '*punctum*' may not always be accidental, it is constructed during exchanges between myself and the person with pain, it evolves out of a process during which those elements which 'prick' or elicit deeper psychological meaning are frequently only recognised when viewing the final photograph.

*I didn't realise until I saw the photograph but it is about having the inner and the outer experience at the same time. It is because you have inserted the collage between my face and my hand. It is about touch' (perceptions of pain, participating patient)*

What is important to remember is that photographs do not just allow us to recollect personal experience; to elicit personal narrative, - they also create it. According to Tagg the production of images 'animates' rather than discovers meaning (Tagg, 1988). I believe it both discovers and animates. It is therefore vital that pain sufferers play an active role in both the creation and the

interpretation. Meaning is being both constructed and revealed during the co-creation process.

## **Semiotics**

I would like to employ semiotic theory as a means of exploring the functioning of the photograph; according to which, the photograph elicits narrative through its organisation '*into a configuration of signs*' (Burgin, correspondence 2010).

These signs can be decoded in a number of ways triggering multiple interpretations. In the medical consulting context the aim of a resource of photographic images is neither to depict every type of pain possible nor to create images in which patients and physicians always agree on the decoding. What is important is that the photographs act as catalysts to eliciting patients' narratives – to what each person needs to communicate and investigate about their unique experience of pain.

Photographic 'reality' is constructed through a discourse of codes and these codes present us with a way in to discussing the subjective reality they reference. Signification is a discursive process not an exact science. In trying to unravel the signs within an image we are placed in the position of many sufferers trying to make sense of the baffling set of symptoms or bodily signs that make up their pain.

*All communication takes place on the basis of signs, most predominantly on the basis of visible and audible signs. To say that one person has communicated with another is to say that each of them has understood how to use and interpret the signs which made up the message between them. ... The photograph is a sign, or more correctly speaking, a complex of signs, used to communicate a message. (Burgin 1976 p 79).*

Semioticians such as Saussure, Barthes and Burgin argue for the structures at work within the photographic surface to be seen as a rhetoric of photography, whose codes are open to analysis in as rigorous a manner as verbal rhetoric. In other words they argue for a visual semiotics.

Barthes, one of the earliest seminal figures to analyse the systems and structures of meaning at work within the photographic surface, began by arguing that as the photograph was exactly analogous to the object it depicted, it was what he called a '*denoted*' image, i.e. a message without a code (Barthes, 1977). He went on to observe that although the photographic message was on the one hand what he termed '*denoted*', there was a possibility it was also '*connoted*' (i.e. that a second or inferred meaning was imposed on it) and that the connoting represented a '*coding*' of the photographic message: '*In actual fact there is a strong probability (and this will be a working hypothesis) that the photographic message too ... – is connoted*' (Barthes 1977 p 19). The photographic paradox, he concluded, was a co-existence of two messages, '*the one without a code (the photographic analogue), the other with a code (the 'art' or treatment, or the 'writing' or the rhetoric, of the photograph)*' (Barthes, 1977 p 19). Each of us will decode the photograph differently, allowing it to reflect different meanings, but the same figures of rhetoric which Barthes and the semioticians identify, will be acting on us and contributing to these interpretations; such as antithesis, ambiguity, repetition and so forth. In sum, Barthes premised this rhetoric of an image on the distinction between denotation and connotation: '*A denotation is what we see, what can be described as simply 'there' in the picture. Connotation is the immediate cultural meaning derived from what is seen, but is not actually in the picture*' (Bate, 2009 p 17).

What I find interesting in relation to the process of making and using the pain photographs in a clinical context is that there are several planes in which '*connoting*' is taking place. There are not only the '*connotations*' of the finished photographic image but those constructed during the processes of production and reception, further '*connoted*' via verbal language. The photograph is not an objective representation nor language a neutral conveyor of facts. However in a clinical context the '*myth*' of objectivity, where constructed connotation assumes so completely the '*'objective' mask of denotation*' (Barthes 1977 p 21), it works in our favour to help validate the experience of illness the photographs are representing. Co-existent with our desire to believe in a photograph as documenting a '*real*' moment is our knowledge that this '*reality*' is constructed by the photographer. This makes it an ideal medium for making real the subjective '*reality*' of another.



## Connotation and denotation:

### Underlying connoted similarities between images/series

The connoted message in Fig 27, made early on in the ***perceptions of pain*** project, is constructed by the juxtaposition of oversize flying or suspended medication bottles and the rubbish dump that forms the background. What is denoted is a collection of rubbish with some medication packets in the foreground. What is connoted is decay, waste, the self as rubbish, the self as a space of abandonment, perhaps abandonment of self-esteem. Privileged within that reading is the issue of 'medication'. Because the medication packets appear to be thrown across the image and are out of scale with the background, our attention is forced towards them so that we read a relationship between them and the discarded overflowing piles of rubbish behind. The reading of the image is affected by the production, by the fact that the medication packets were placed on top of the original photograph of rubbish and re-photographed, so skewing the relationship of scale. The pain sufferer who created this image with me described how, when at last her medication appeared manageable and stable, someone would come along and change it and it would become unbalanced and overwhelming again. When she took this image, within her selection of photographs, to discuss during her consultation with Charles Pither, he noted that she hadn't mentioned the physical site of her pain during the consultation at all. Looking at the image and the rubbish depicted she said '*that is what I need to say*'.

What became evident when starting on the ***face2face*** project was that there were many overlaps in terms of references, forms, colour, and metaphor not only within series' of images but also between series' as many resonated with the previous project ***perceptions of pain*** - providing further evidence that we might be 'revealing' a generic iconography for pain. For example, the theme of medication as an issue of contention described earlier has already emerged within images in the new project at UCLH with facial pain sufferers. Compare for example Figure 35 from ***face2face*** with Figure 27 from ***perceptions of pain***.

What is denoted is a pile of tablets and some letters torn from a newspaper; the connoted meaning is constructed through the relationship between the letters and the tablets as much as by form and colour. The relationship is reinforced through colour. The red pills pick up the red of the letter 'T'. The limited palette,

red, black and white (laden with culturally dependant symbolism) integrates word, object and background. The letters are not any old letters but torn from a newspaper, part of the information industry, they document and authenticate, while connoting fragmentation and disruption. We are not given the whole word, the 'D' is missing from the beginning and the end, and it is out of sight, off frame. The arc of the story is incomplete, we do not see the beginning and end of the journey; rather we are thrown right into the middle of the experience. Without the letters, the tablets scattered across the image would be just tablets, signifying possibly a route to recovery, but here juxtaposed with the word 'devastated' they clearly have negative rather than healing connotations. Medication, as in the previous project, is presented as a symbol of frustration and dependency, of being out of control - life-threatening rather than life-giving. The image demands that medication and its inherent power-dynamics be discussed.

Equally, we could compare Figure 36 from *perceptions of pain* which 'denotes' a rotting apple with Figure 29 from the *face2face* project denoting mouldy bread. The objects denoted are different but the 'connoted' meaning is similar. The apple in Christian mythology connotes a fall from grace, a framework of good and evil. It is an organic object usually associated with health, is nutritious, life giving ('*an apple a day keeps the doctor away*') a result of growing and blossoming. However, here the organic object is decomposing, there is little nutrition, it will be discarded, the rottenness or 'disease' is overtaking the healthy tissue unseen until it reaches the surface. It is not only disintegration that is connoted but also a hidden partially secret process of disintegration. The section of this apple also fortuitously bore some resemblance to a human profile, hence its selection. The sufferer I made this image with remarked on how

*Pain is a concept you can look at in so many different ways. It is like an apple which is rotten from the inside. There is the central core which is the centre of the pain – which is what it would be if it were in the spine – and it comes through and affects the skin. ... you can't see it to start with until it increases and increases and reaches the skin and then people see it. (Pates in Padfield 2003 p 103).*

Similarly, in Figure 13 bread is denoted, being another substance usually perceived as wholesome, life giving, a basic food, with equally strong biblical

symbolism, but again it is depicted as decomposing and disintegrating, becoming part of and almost re-forming its own landscape. The facial pain sufferer I made this image with described her experience of pain as a 'shadow sandwich', itself a powerful metaphor. Interestingly she chose to make the 'sandwich' out of mouldy rather than nutritious bread, which she had propagated between sessions. The sensation she wanted the image to signify was a claustrophobic one, a sense of being stifled. It was looking at the photographs together and comparing them that prompted her to observe that the outline of the shadow on some of them needed to be less clear; the photograph that resonated more for her was the one where the mouth was less visible. She described her experience as:

*W5: kind of stifling... feeling, merging into something... then the skin, what would be the skin, is really the mouldy bit ... when it is really black, it's the kind of festering feeling in it*

*DP: I was going to ask you what was significant do you think about the mould or the mouldy bread?*

*W5: cognitive impairment, your memory not being able to function properly, and just like fatigue .. ... not being able to see, like I said my peripheral vision feels a lot clearer now... it's just the most bizarre experience when your face muscles aren't moving and, your speech muscles are going wrong and it's funny that there is no mouth there is there?*

What the images also reveal is how photography reinforces a sense of authenticity, we believe in the subjective reality they appear to document because we still associate it with the ability to provide authentic documentation of 'reality' - however much we know that that 'reality' has been constructed or manipulated by the artist. Photography could therefore be said to be acting to redress the doubt of others because of the lack of any other outward manifestation or adequate language with which to evidence the pain.

### **‘Authenticity’ and the photograph: Sontag, Burgin, Bate and Berger**

Sontag draws our attention to the intrinsic relationship between photography and reality when in *On Photography* she writes: ‘*A fake painting (one whose attribution is false) falsifies the history of art. A fake photograph (one which has been retouched or tampered with, or whose caption is false) falsifies reality*’ (Sontag 1979 p 86). It is precisely because photography is so frequently accorded an authentic relationship with reality that it works so well for us in these projects. The only ‘reality’ that matters in eliciting narrative from patients is their reality, - how they experience their pain, the meanings they confer on it. It is not that other realities such as the clinician’s understanding of pain mechanisms, physiology or the likely trajectory of pain experience, the likely impact of drugs on certain conditions, realities of the constraints of the NHS etc are irrelevant, they are far from that, but in seeking to elicit, and understand how a patient is experiencing their pain, the world and belief system into which they are fitting it, the significance they ascribe to it, it is the authenticity of the patient’s story which needs to be valued, and the photograph helps do that. It provides tangible ‘proof’ for the pain. For an ‘evidence based’ culture, proliferated with spreadsheets and ‘outcomes’, the photograph provides an alternative certainty out of something nebulous and difficult to ‘evidence’. Looking at the photographs created in these projects with pain patients it is difficult to believe that we could possibly have arrived at those images without them having experienced sensations as baffling and contradictory as their photographic representations. Photographs therefore accord a reality and a materiality to subjective truth.

Berger states that the ‘*relation between what we see and what we know is never settled*’ (Berger 1972 p 7) and this is never more true than with photography. His writing continually reminds us that a photographic image inevitably embodies different ways of seeing: that of the photographer/artist and that of the viewer. It triggers a symbiosis of different perspectives, different histories which can never be ‘settled’ but whose relationship is frequently unacknowledged in deference to photography’s accepted ability to record and preserve ‘real’ moments. Sontag reminds us that ‘*Instead of just recording reality, photographs have become the norm for the way things appear to us, thereby changing the very idea of reality, and of realism.*’ (1979 p 86). She turns the relationship between ‘reality’ and photography on its head by suggesting ironically that photographs do not simply

render reality realistically but that it is reality which is scrutinized, and evaluated, for its fidelity to photographs (Sontag 1979 p 87). Photography is not a direct index of reality yet it is inevitably involved in the construction of that reality and it inevitably implies an exchange of realities. It is imperative that clinician and patient therefore are drawn into a negotiation across the photograph, that its meaning is discussed and negotiated, that the narrative it is giving birth to in that room is acknowledged as authentic. I believe the photographic medium with its historic role as recorder of reality supports this process.

The camera was originally viewed as objective, as a mechanistic device which used light alone to bring into being a visual 2D record of a 3D object without intervention from the photographer. In Sontag's words the photographer was felt to be '*an acute but non-interfering observer – a scribe and not a poet*' (Sontag 1979 p 88). She goes on to argue that photographs have become not only evidence of what is there but of what an individual sees, what they select, that photographs are evaluative (ibid p 88). We still believe that the photograph produces an authentic representation of 'real' moments caught in one time and preserved for another. Photographers and story-tellers are Berger's '*Deaths Secretaries*' referenced fleetingly in *and our faces, my heart, brief as a photo* (1984). We do not generally understand their function to be creating the truths that they preserve, but this is almost always at work to some degree. This is particularly so during the co-creation process between pain patients and myself, and in the reviewing process between pain patients and their clinicians. It is the subjective truth of those with pain which is not only being revealed, but created, and then viewed as if revealed. The photograph, like a wound, is opening to reveal a hidden truth, in Sontag's words '*the photographer discloses*' (1979 p 92), but the photograph like the 'wound' is continually remaking itself.

Many contemporary lens based artists such as Jeff Wall <sup>1</sup>, Thomas Demand <sup>2</sup> and Sarah Pickering <sup>3</sup>, consciously play with notions of reality and authenticity. Photography's relationship to such notions serves to authenticate experience otherwise difficult to visualise and difficult to 'evidence' in a medical arena. The authenticity of patient's narratives are queried and discussed frequently in medical literature (Shapiro 2011)) but I can find no reason for and no value in not authenticating an individual's subjective experience of pain.

Another theme relevant to these projects which runs through Susan Sontag's writing, particularly '*regarding the pain of others*' (Sontag 2003) is the danger of aestheticising other people's experience of pain; the danger that due to the prevalence of photographic images of disasters, we have become inured to their effect, so they no longer necessarily elicit affect.

*Despite the illusion of giving understanding, what seeing through photographs really invites is an acquisitive relation to the world that nourishes aesthetic awareness and promotes emotional detachment.*  
(Sontag 1979 p 111)

Conversely for us it is perhaps the very emotional distance and detachment produced by the photograph which allows people to talk about things which are so painful, personal and difficult to articulate. The focus of attention is no longer on the person with pain, it is relocated within the space of the photograph - the pain is no longer trapped within the space of the body but placed within the confines of photographic paper, and therefore maybe less personal, less embarrassing or awkward to acknowledge. In choosing to photograph the cuts on her arm from self-harming, one of the participant patients in ***perceptions of pain***, (Padfield 2003 pp 42-43) was making an image of what were already images of her pain, but not acknowledged as such (see fig 37). It was a courageous decision and an even more courageous one to select that as one of her images to be printed and enlarged to over a metre x a metre for inclusion in the exhibitions '*to take the stigma away from self harming*'. Reviewing the image in our 1:1 workshop, she had observed that: '*Seeing the photograph made me realise what I had done to myself*' (participating patient).

A distance is created between the feelings experienced and the act of telling them, just as Sontag (2003, 1979) and Berger (1982, 1980, 1972) suggest, a distance is created between the experience photographed and the emotions elicited in the viewer. This distance in this context works for us. Perhaps we need emotional distance in order to be able to grapple with feelings we have not been able to express or sometimes to recognise.

*the aestheticizing tendency of photography is such that the medium which conveys distress ends by neutralizing it. Cameras miniaturize*

*experience ... As much as they create sympathy, photographs cut sympathy, distance the emotions.* (Sontag 2003 p 109 – 110).

What is it that this aestheticizing does, this distance does? One of the things that I believe it does is to open up the photograph and its significance to multiple readings. The interpretation is not pinned down to one reading but is a relatively open space onto which those in pain can project the experiences they wish to talk about. In this way the images are perhaps not so far off the TAT<sup>4</sup> cards developed in the 1930's by Murray and Morgan for use in mental health services (Murray 1943. See also Morgan 1995). However we are not using them to designate labels or identify social behaviours or specific conditions, we are using them as triggers to a more open and explorative dialogue. An aesthetic space, such as a photograph, allows for ambiguity, which in turn creates a space for further exploration of meaning.

## **INTERPRETATION:**

### **A space for ambiguity**

It could be said that one of the dangers of language, particularly in the health setting, is that participants assume they understand each other even though at times they can be speaking of very different experiences. The meanings we attach to words, particularly for complex and subjective experiences such as pain, are dependant on cultural, gender, religious, historical and ideological positions, amongst others, modified by our personal narratives. In a recent article in the journal PAIN Owen Hughes rightly draws attention to the danger of using words without checking the picture they generate in someone else's mind. *'The meaning intended by a doctor's words are often not what the patient hears'* (Hughes 2010 - 48). The reverse is equally true, that the meaning intended by a patient's words are not always what the clinician hears.

More in parallel with poetry, it is easier to recognise that we all ascribe different interpretations to photographs, we recognise their ambiguity. Photographs therefore force us to recognise the chasm between our different individual perspectives and the limits of language available to us to cross this space. As a

result we are forced to mediate language via the image and vice versa to unravel enough meaning to arrive at a shared understanding. In this way, photographs of pain used within medical consultations can enhance doctor-patient dialogue, equalising the physical, linguistic and metaphorical space of the consulting room, provoking the co-creation of new ways of 'knowing'. Photographic images can give tangible form to confusing sensations, providing a shared aesthetic space within which to negotiate, both with the 'other' and with attachment to previously held perceptions. It is this collaborative search for meaning they stimulate within the consulting room, which I believe validates the pain cards we created as a communication tool for use in the NHS.

This level of ambiguity could be said to come close to Barthes' third meaning' described in *the third meaning: Research notes on some Eisenstein stills* in *The Responsibility of Forms* (Barthes 1970 tr Howard). Barthes identifies three levels of meaning: (i) a denotative meaning, (ii) a connotative meaning and (iii) an obtuse meaning (French '*sens obtus*') defined as a '*poetical grasp*' (Barthes 1970 p 53), which is not so much 'read' as received' (Barthes 1970 p 42). Barthes explains this meaning in terms of an excess of signalling, that the obtuse meaning is extraneous to the obvious meaning (Henriksen et al 2011 p 283). Barthes defines the 'obtuse meaning' as '*... extending beyond culture, knowledge, information ... Obtuse therefore suits my purposes well* (1970 p 44). It also suits our purposes well in suggesting a meaning, which may be tinted as seen through a 21<sup>st</sup> century lens, but which allows us to know the photograph and by reference the body through non-intellectual means, reaching beyond what is knowable through language.

### **Barthes' third meaning**

Interestingly, Derek Attridge in his analysis of Barthes' 'obtuse' meaning does not place it in opposition to the *punctum* described earlier. Instead, he posits that looking closely at Barthes' texts the metaphorical opposition between *punctum* and *obtuse* meaning appear to collapse (Attridge 1997 p 78). '*The obtuse meaning is even said at one point to be a "penetrating feature"* (Barthes 1977 p 48); *conversely, it is the punctum that "bruises"* (Barthes p 27).' Attridge goes on to cite Barthes own description of the punctum suggesting that it comes very close to his definition of the 'third meaning'. '*The effect is certain but*



*unlocatable, it does not find its sign, its name; it is sharp and yet lands in a vague zone of myself; it is acute yet muffled, it cries out in silence.*' (Barthes 1993 52-53). What is significant about the third meaning, whether or not it shares aspects of the punctum, is that it happens at the point of viewing and as a result of an individual's emotional response rather than as a result of intellectual perception. 'The third meaning is the third meaning to somebody' (Lauridsen, 1991: p 129). In Henriksen and team's chapter analysing Sara Bro's photomontage cancer narratives, the authors define the creation of third meaning as '*an offspring of the meeting of image, text and reader.*' (Henriksen et al 2011 p 283). It is this liminal space between creator and viewer and between image and text where I believe the potency of such photographs lies and its underpinning with an accorded authenticity which reinforces the potency of this space.

If we are considering the plurality of readings photographs promote, and the role of viewer as well as maker in their creation, then we return again to the photographic space as a space of exchange. In this context it is valuable to think about power relations within the photographic exchange and highlight the return of power which control of the lens can confer on a subject when that subject becomes part of the image-making process.

### **Reversing the power dynamic through control of the lens: Spence, Foucault, Tagg**

*Going into hospital is pretty traumatic and upsetting. You have no power at all and one of the ways I had symbolic power was to photograph what was happening to me. In hospital you are completely infantilized and any right to make any decisions is taken away from you. You have no power at all ...* (Spence 1987).

Medicine has changed much since the 1980's but Spence highlights two important points; that there is always an element of infantilisation when entering the space of the hospital, asking other people to take care of your body, and there is always a sense of control over what is photographed by the person behind the lens. If these two come together and the subject being photographed is a person in pain, then there can be a dangerous inequality of

power. Having control over how that illness is visually represented is essential for any sense of autonomy and wholeness for the person who is ill, and for any sense of responsibility in the recovery process. Control of the lens confers power over how an illness is seen and understood by others. For this reason it was vital in the **face2face** project that patients participated in the creation of the images. By the time they have arrived at a pain consultation pain sufferers will almost inevitably have been through countless investigations and been on the passive receiving end of countless medical imaging processes. Participating in the co-creation of photographic images returns agency, and I would suggest that the process can only be beneficial when sufferers have considerable agency. The last thing pain sufferers need after what are frequently long journeys through the diagnostic corridors on the receiving end of the medical gaze is a re-appropriation of their experience by an artist. The space of exchange is therefore a space of tension, of risk for patient and artist. The patient needs to have control over how his or her experience is seen and witnessed by others, but in this project the aim was not for patients to explore their experiences within the framework of art therapy producing images completely themselves, but to explore these experiences within a framework of fine art, where the images needed to communicate their experiences to others and be placed in a public space to promote awareness and understanding. The images had a function to fill as well as a process. Therefore there was also an aesthetic risk for the artist. The process of co-creation was a highly sensitive one involving negotiation and risk on both sides.

## **Spence**

The work of photographer and activist Jo Spence has become an iconic example of how photography can be used to regain ownership over illness. In many ways her work could be seen as a precursor to my work, although where she explored her own experiences, I am working with others to explore theirs. Inevitably during this process I learn a lot about my own experience and some of this must in turn be informing our co-creative process.

Spence was no newcomer to photography when she became ill with cancer in 1982 and it is her skill and understanding of photography as a medium which made it such an effective tool in her hands. Much of the strength of her

photography is due to her considerable experience in documentary photography, photography as a form of social activism, and photography as an art form, before using it to explore her own potential sense of helplessness in the face of the medical edifice.

Recognising the widespread marginalisation of some categories of sickness and illness she became alerted to the importance of creating alternative positive cancer narratives (Dennett 2011 p 224) and of exploring her own illness narrative through a medium under her own control - the camera. In his chapter on Spence's auto-therapeutic survival strategies in a special edition of *Health Journal* on the representation of illness (Dennett 2011 pp 223 – 239 ), her ex partner and colleague, Terry Dennett, describes Spence's longstanding interest in recording every day personal events, '*documentation and surveillance*' as she called it, citing from her unpublished workbook where she notes:

*When I first learned I had Cancer ... I used my camera as a third eye, almost as a separate part of me, which was ever watchful, analytical and critical yet remaining attached to the emotional and frightening experiences I was undergoing ... I think of photography as an act of writing – one picture worth many words – words that I and other cancer people find hard to articulate during illness (cited Dennett 2011 p 225).*

### **'Autotherapy' and the mirror**

She carried this into her photographic exploration of her own experience during the cancer diagnostic and treatment journey and encouraged others to '*pay more attention to the everyday and put private life work into the public domain, both as an act of social liberation, and a step towards giving previously ignored and forbidden personal subjects like illness a public face.*' (Spence 1986). In the first passage quoted Spence highlights both the way photographs resonate to produce meaning beyond what can be pinned down or constricted into one 'interpretation' or one text. This makes photography a particularly versatile medium for communicating and making real to others aspects of personal illness experience. In the same passage she also highlights the critical distance constructed by the photograph and the retention of power over how an illness experience is seen, though power over the gaze.

She began by initiating a series of 'self-dialogues' using a tape recorder, developing this auto-therapy further through a series of illness diaries in cheap A3 scrapbooks containing a mixture of annotated photographs and text (Dennett 2011). She also started reworking a technique of 'photo theatre' she had used in the project '*Remodelling Photo History*' transforming it to a more personal therapeutic imagery, influenced by radical theatre directors such as Brecht, Boal and Dario Fo (Dennett 2011). Using the notion of audience actor interaction she became both audience and protagonist, a 'pretend therapist' initiating dialogue between herself and herself as therapist, dressed up in nurse's uniform and wig. She staged these dialogues in a mirror, which allowed her to create a distance between what she was witnessing, while exploring how she felt emotionally. Dennett describes how she used the mirror like a camera, allowing it sometimes to substitute for expensive film (Dennett p 230) and then moving on to setting up an actual camera next to the mirror (see fig 38).

Looking at the stark, in some ways challenging, images as in figs 39, during teaching sessions with medical students I find the most frequent issues triggered for discussion are the use of photography as an attempt to regain ownership of the body and illness, and the attempt to create coherence and a holistic whole out of the fragmentation which so often happens in a hospital setting. Students notice the references to hospital property such as sheets, pillows and gowns which all have their affiliation stamped across them, signifying hospital ownership, they also make observations about the fact that she is wearing glasses, so hiding something of her identity.

They frequently relate this to medical photographs which maintain patients' anonymity by putting a black band across the eyes, simultaneously removing any sense of identity. Many of the students object because of the removal of individuality it effects. Spence's purpose may have been entirely pragmatic to hide the bags under her eyes and exhaustion showing within them, in her words '*to stand tall*' and appear how she is '*not supposed to look when sick*' (Spence 1986). They may also be part of her development of the 'intruder system' within the photograph.

## The intruder

Borrowing from Brechtian Theatre the '*intruder*' is something the viewer doesn't expect to see in the picture, something which problematises it, which removes it from a normative reading thus forcing the viewer to rethink the content, although in this image the relationship of text and breast also performs this function. The method drew upon photographer and sociologist John Heartfield's contention that the sign is primarily the arena of an ideological struggle, and that the re-arrangement of naturalistic signs is an important vehicle for the promotion of a political message (Radley, 2009 p 68). Of this photograph (see fig 39 ) Spence herself writes:

*Before I went into hospital in 1982 I decided I wanted a talisman to remind myself that I had some rights over my own body. Terry Dennett and I set up a series of tableaux, each with a different caption written on the breast. This is the one I took with me* (Spence 1986 p 157).

In his insightful and extensive investigation into representations of illness, sociologist Alan Radley observes that in calling this series of images '*tableaux*', Spence was '*making clear that these photographs are records of dramaturgical creations that took place ... are actually traces of carefully constructed enactments, the form of which the viewer is invited to deconstruct ... they problematise the relationship between the figure and the artist*' (Radley 2009 p 70). He cites Dennett's description of their working method, '*In this way we have a twin performance; the staging and acting out of a tableau for the camera, and then a two-dimensional signifying performance on paper.*' (Spence 1995 p 78). Within this particular image there may well be reference to the anonymity effected by bands the students noticed in contrast to the ownership the text implies, exemplifying a plurality of meaning and signification.

Not irrelevant to the photograph also is ownership of a distinctly female part of the body. In an age where the medical gaze was frequently a male gaze, Spence used photography to expose the less visible or acknowledged implications within this fusion and to return control of the gaze to the patient and subject.

## **Foucault: Power-dynamics and the *medical gaze***

Any discussion of the gaze cannot ignore the theories of Michel Foucault. Foucault's exploration of the emergence of a clinical and medical gaze began with his observations of the end of the eighteenth century as the beginnings of modern medicine, which initiated a changing relationship between the visible and invisible, revealing through 'gaze' and 'language' what had previously been below and beyond the doctor's domain. 'A new alliance was forged between words and things, enabling one *to see and to say*' (Foucault 1963 p xii). With the emergence of this concept of the gaze, and in particular the medical gaze, came a parallel unpacking of the power dynamics inherent within it, the ways in which it was intrinsically linked to a language of objectivity, based on a correlation of the visible and the expressible:

*An absolutely new use of scientific discourse was then defined: ... It was necessary, then, to place medical language at this apparently superficial but in fact very deeply embedded level at which the descriptive formula is also a revealing gesture ... the balance of experience required that the gaze directed upon the individual and the language of description should rest upon the stable, visible, legible basis of death* (Foucault 1963 p 196).

Foucault expands, describing how it became possible for the object of discourse to equally well be a subject, without the figures of objectivity being in any way altered, claiming that it was this '*formal reorganisation, in depth, rather than the abandonment of theories and old systems, that made clinical experience possible; it lifted the old Aristotelian prohibition: one could at last hold a scientifically structured discourse about an individual*' (Foucault 1963 p xiv).

Psychiatrist, Andrew Hodgkiss, asserts that Foucault's introduction of the term 'medical gaze' shifted reliance on the patient's words to examination of his body. Hodgkiss also asserts that Foucault argues that a transformation in the power relations between doctor and patients was then at stake. From being servants of the eighteenth-century French gentility, physicians in public hospitals began to see large groups of poor patients as research fodder and they offered their bodies as objects for the medical gaze at the cost of respect for their subjectivity (Hodgkiss 2000 p2). The same is true with the beginnings of the NHS in the UK. There is a consequence enacted in the unequal power dynamic between

clinician and patient still apparent, and perhaps nowhere more so, than in pain deemed to be '*without lesion*'.

This discourse of objectivity and visibility omits inclusion of the invisible, the intangible, the emotional, and all the aspects of narrative which so affect those with pain, who find themselves in a situation where they feel they have no power and are subject to fear and uncertainty. Foucault explains 'the medical gaze' as how clinical experience was soon taken '*as a simple, unconceptualised confrontation of a gaze and a face, or a glance and a silent body; a sort of contract .... by which two living individuals are 'trapped' in a common, but non-reciprocal situation*' (Foucault 1963 p xv). Medical discourses are changing, but the conception of an objective or 'detached' gaze is still very present. Medical historian Ruth Richardson, prefers Hunt's term of '*Necessary Inhumanity*'<sup>5</sup>, as a more honest definition of what has come to be called '*clinical detachment*' (Richardson 1988 pp109 -122 and 2000 pp 104 - 106 ). Richardson believes that if we return to the notion of 'necessary inhumanity' we might be more conscious of what is being enacted that:

*it might become evident that clinical detachment is not a simple acquisition, but a spectrum of sensibility which can range from extreme cruelty to conscious empathy. Most of us are able to discern that Nazi doctors were off one end of the scale but it is also important to be aware that so too is some of the behaviour in our own country, insitutionalised in our own health service, even in our own time*  
(Richardson 1988 p 121).

Richardson goes on to conclude that if we re-embrace the term 'necessary inhumanity' now, it might mean '*an awareness of its dangerous potential, which in turn might mean there would be less of it about*' (Richardson 1988 p122) . I feel there are still historic vestiges of paternalism in the drive for so-called 'scientific objectivity' and the 'detachment' Richardson references and the enthusiastic embracing of 'evidence based medicine' by the medical profession. Objectivity and evidence are not neutral concepts. Objectivity I would suggest is unobtainable. There is always an interpretation of data, there is always a history, personality, and ideological and cultural assumptions behind the 'objective' gaze of the scientist or doctor. Just as it might be important to acknowledge the 'inhumanity' of 'detachment' it might perhaps be helpful to acknowledge the lack

of neutrality within any interpretation or medical exchange rather than hiding behind notions of objectivity, and its attendant power.

Foucault himself asserts that power is not something inherent to particular individuals, which certain people are endowed with, but the name given to a complex strategic situation in a given society (Foucault 1963). This suggests that, like Spence, we are responsible for unpicking those strategies which society has negotiated and finding ways of reclaiming some individual power for ourselves within the hospital setting in order to reclaim responsibility for our own recovery - to be part of our own healing process. Photography and control of the lens, is one tool for initiating a reversal of the gaze and a reclamation of power.

## **THE PHOTOGRAPHIC PORTRAIT:**

### **From where the gaze starts: The Face**

Facial pain intensifies all the problematics associated with identity already present with any form of chronic pain. For some pain patients the face is a unique container or index of identity so that any change in the face impacts on perception of identity. It is also the canvas we use to express pain and emotion and therefore has a unique place in the ways we interact with and understand each other. The photographic portrait which embodies something of this interaction, provides us with an opportunity to explore its nature – the ways we receive and process information from another, the ways we project onto another - in other words portraiture is capable of exposing elements of social exchange. What insights therefore can we glean through a process of portraiture with people for whom the face carries such potency and for whom the face has become such an intensified locus of suffering?

Specific regions of the brain are activated when we look at a face or a portrait (Roberts 2006 p 29) and it plays a central role in our social interaction. One interviewee during the **face2face** project described the role of the face in the following way, illustrating its central role in communication:



*Well first and foremost it's identity, all of us have something unique about the face and it's what makes us. The key thing about the face is the identity, you've got the mouth for speech and eating, the nose for breathing which is an essential part of being alive, eyes for visual and the ears which are attached for hearing and everything else I suppose, cheek, forehead, it's part of, with the head that links in with the brain activities as well, so key part of the human body.'* (**face2face** Study CodeT8).

The face and thus the identity it carries, is re-made every time it is viewed by another, every time it is photographed, and every time that photograph is re-viewed; it is remade in the minds of the bereaved when a photograph triggers an image of the 'lost' person or when the re-imagined face enters a dream-life. The face is seen by many as an index of identity, and the photographic portrait perhaps an index of that index.

Traditionally the face and the portrait have been conceived, to use a cliché, as 'windows to the soul', that the artist through the portrait somehow presents the 'real' character of the sitter. Current perceptions of the face still worryingly link back to this almost physiognomic conception of facial expression as indicator of character and identity.

Of the face, participants in the **face2face** workshops in their evaluation forms said it was:

*'a window', 'a window to the soul', 'The face is the most important door to our inner world through its manifestation of expression.' 'To mirror the soul!' 'a doorway (esp. the eyes) to your soul.'" It is a window to the world' and an interesting one 'I think the face signifies emotions but can conceal as much as it reveals'.*

Of the portrait they said:

*'A reflection of the soul, the essence of the person'., 'Reflection of a face/ head/ personality – what's happening in a person's life.' 'Yes. A face*

*telling us about a person not only in terms of appearance but also emotion.'*

Nearly all of those interviewed felt that the photographic portrait could reveal something about the sitter's personality and that it would provide an 'authentic likeness'. Similarly in answer to the question '*what is a portrait*' visitors to the **face2face** stand (part of the Eastman Dental Hospital's presence at the UCLH Trust Open Day, Dec 2009), replied when interviewed:

*'A likeness of the sitter, it brings out the character of the sitter and maybe things that interests them.'* (T7)

*'I think a portrait is ... trying to capture that person in a particular mood.'* (T8)

*'A portrait. Well there are two types I think. One is a realistic thingy and one is a personality thingy.'* (T14)

*'A physical likeness that gives you an idea of what that person is like and that what they're feeling and what their emotions are.'* (T20)

*'Not necessarily a complete likeness but it's somehow capturing the character. Representation of the spirit of the person as well as the visible...'* (T22)

*'Well I think a portrait is important, it can be a record of how a person was at a particular time in their life so it's a historical document on the level of, you know, the human experience so obviously any photos or paintings by artists of portraits are hugely interesting to people because they're documents of humanity and the history of humanity.'* (T23)

In photographic portraiture these responses ignore the fact the identity or 'soul' we are witnessing is being created and mediated through the gaze of another – the artist or photographer. The fact that the identity is so largely constructed by the photographer often remains unnoticed. For example in the same series of interviews when asked to describe a portrait, T24 asserts surprisingly that she would rather have a photographic than a painted portrait because it would provide a more truthful 'likeness'!

*'I would think that a photograph would be more the true image of the face than a hand-painted image ... I would rather to have a photographic image from a camera than hand-painted image because the hand-painted image may reflect the artist's mood, time of day'. (T24)*

### **The photographic exchange/encounter**

A more nuanced critique of the photographic portrait and the exchange between subject and photographer emerges not only through Spence's work as previously discussed but through the practice of many contemporary fine art photographers such as: Alexa Wright, Dryden Goodwin, Jiri David, Annelies Strba, Kathy Kowalski, Susan Hiller, Thomas Ruth, Sarah Pucill, Rosy Martin, Helen Sear, Nancy Burson, and many others. I will be looking at the work of some of these artists later in the chapter, in particular Dryden Goodwin and Alexa Wright, but for now I want to focus on the nature of the exchange within portraiture and the role of the face in our interactions.

Portraits are ubiquitous and particularly in Western culture tied up with ideas of who we are. The relationship involved when handing over to an artist or photographer the task of 'representation', of communicating that identity to others is a sensitive one. How much does it differ in its power imbalances from handing over your body to another to be healed or operated on? For some, the body is less central than the face to our sense of being than our identity: *'the body is not important'* (Ozarovsky in ***duet for pain*** Padfield 2012).

In current discourse on the photographic portrait the nature of that transaction has become pivotal. How much has the subject consented to being photographed, how much control over the location, the context, the aesthetic has the subject had, is central to the outcome and ethics of the process. Each photographer explores these notions in different ways but they are always present whether conscious or unconscious. Is the portrait an objective impression mediated via another, or does it embody a meeting of subjectivities, or does one dominate over another? There are many issues and questions raised inevitably by the portrait encounter, for example whose identity is being constructed or is the nature of identity so multifaceted that several are represented within the single image. If one facet of identity comes to the fore,

who has selected it to become prominent? There are questions around 'staging' particularly relevant to the medical imaging encounter where the self is being exposed through x-rays, ultrasound, magnetic imaging, etc. Is the identity produced known and communicated primarily by the visual or by verbal material? There is also the ever present notion of authenticity, what an authentic portrait might mean, for example authentic to whom and against what? These will be very different in clinical and creative portrait encounters. The other presence in this relationship is that of the viewer, raising the issue of voyeurism and the position of the viewer.

What I hope for from a portrait is that the answer to many of these questions is '*it is negotiated*'. Within the co-created 'pain portraits' made during **face2face**, the premise has been to involve the subject, the person whose pain is being re-presented in that process of representation. They are not portraits *of* them but portraits made *with* them.

To some extent the contemporary photographic portrait always has an element of co-creation, but how much is acknowledged differs from artist to artist. Ethically, in my work the pain portrait hovers on a tight-rope between pain sufferer and artist, between the tangible and the intangible, the subjective and the objective. Its material, its processes and the relationships negotiated are delicate, requiring trust on both sides. The delicacy of its challenges could be encapsulated in the poignant question from one of the **face2face** participants, '*how do you photograph a whisper?*' (Study code I2).

## THE BEGINNINGS OF PORTRAIT PHOTOGRAPHY IN 19 C. MEDICAL DISCOURSE

### Photography as part of the armoury of science: evidence gathering

At its inception in the middle of the nineteenth century, photography rather than being a whisper or indeed an art form started life as a solid tool in the armoury of Science; it provided evidence for emerging theories but it also contributed to them. In the latter half of the century, for example, it became the key to the new scientific physiognomy (Gilman 1996 p 164).

*That the outer man is a graphic reproduction of the inner and the face the expression and revelation of his whole nature, is an assumption whose a priori nature and hence certainty are shown by the universal desire, plainly evident on every occasion to see a man who has distinguished himself in something good or bad, ... finally Daguerre's invention, ... affords the most complete satisfaction of that need.*  
(Schopenhauer 1974, 2 p 634, cited Gilman 1996 p 164).

Imaging technology prior to photography was seen as having drawbacks because of its dependence on human skills (Hamilton 2001 p 57). Theodore Gericault, for example, had been commissioned to create studies of patients with different forms of 'monomania' by a doctor at the Sâlpêtrière in Paris, between 1821 and 1824, before either Duchenne or Charcot arrived on the scene, but these images were deemed too emotive, too individualised to be used as scientific material.<sup>6</sup> Historian Peter Hamilton claims that whereas prior to photography images were illustrative - they could represent - with the discovery of photography images were able to be used '*in their own right as evidence*' (Hamilton 2001 p 57). The medium was taken up enthusiastically by scientists and particularly by medicine, with little critiquing of the construction of 'evidence', embedded in the photographic process, the *Lancet* in 1859 stating:

*'Photography is so essentially the Art of Truth – and the representative of Truth in Art – that it would seem to be the essential means of reproducing all forms and structures of which science seeks for delineation ....'*

(*Lancet* Jan 22, 1859, p89).

### **The promise of 'objectivity'**

Photography promised objectivity; photographs were deemed able to produce (and thus with hindsight we could say 'construct') evidential knowledge. According to Hamilton this '*produced a paradigm shift in ways of thinking about knowledge itself, and played a central role in the success of the sciences in the nineteenth century*' (Hamilton 2001 p 57). There is a parallel development of the role of the camera as a technology for surveillance and classification on the one hand which is parallel with an increasing demand for domestic photography and

for 'social photography' of occupational types on the other (ibid p 57). The social and scientific world photography was employed in meant that the relationship between sitter and photographer was navigated very differently from that of contemporary portrait photography. Never more so than when the portrait was taken within the hallowed halls of medical or state institutions and served not only to represent identity or likeness but claimed as a scientific tool in the advancement of medical knowledge.

In the nineteenth century, this was particularly evident in the use of photography to 'research' and 'evidence', or make visible and thereby more understandable, conditions with then invisible or unknown causes such as hysteria and epilepsy. The practice was notoriously promoted in France by the 'father of neurology', Jean-Martin Charcot in the 1870's at the infamous Sâlpêtrière Hospital in Paris, and his mentor Duchenne du Boulogne, who had also spent some time at the Sâlpêtrière. They were also practised in England by Dr Hugh Welsch Diamond at the Surrey County Lunatic Asylum in England, Henry Hering at Bethlem Asylum, T.N Brushfield at Chester County Lunatic Asylum, the distinguished psychiatrist Sir James Crichton Browne, Medical Director of the West Riding Asylum in Wakefield, and several others . A very different exchange is enacted during these encounters where the subject appears to have little control over the construction of their identity. Here the fusion of the medical with the male and photographic gaze effects a stark in-balance of power passing over the usually female, unwell sitter with little social or economic power (in an age when women's identities were largely defined in relation to men), contrasting markedly with the aims of our co-creation process in **face2face**, and resonating ominously with theories of objectification and surveillance.

### **Issues of power in the hands of 19 c. doctor-photographers**

The discrepancies in power may be more complex and more nuanced however than first impressions imply. In writing her insightful book on the photographic subjects of the prominent neurologist Charcot, '*medical muses*', researcher Asti Hustvedt (2011) describes how she started out with a similar preconception to that which I have always held, ie that '*the hysterics were victims of not only their home lives, but of a misogynist institution led by the tyrannical Charcot*' (2011 p4). For me this position was only reinforced after viewing the images of

Charcot's photographers, Richer, Regnard, and Londe, in which the subjects appear as directed stars in the construction of identity, and the performance of illness, not only for the erudition of the medical community but the entertainment of fashionable society. Surprisingly, Hustvedt goes on to acknowledge that *'despite my intention, the more I read, the more I found myself admiring Charcot's brilliance. I also became a reluctant fan of some – not all – of the members of his coterie, a groups of physicans who worked with him at the Sâlpêtrière'* (Hustvedt 2011 p 5). Is there an implication in this that the encounters were more complex and the knowledge obtained more significant than exchanges which we could dismiss as outright abuses of power? What is happening within those exchanges? What is being witnessed? What is being revealed? Are there ever occasions when such controversial practices reveal useful information - and do the ends ever justify the means? These are not questions to which I have an answer, and they remain uncomfortable. To a contemporary sensibility the unequal distribution of power is highly problematic, calling into question any knowledge arising out of it. In his insightful analysis of the construction of hysteria via photography, French philosopher and art-historian, Didi-Huberman highlights the complexities of the extraordinary complicity between patients and doctors at the Sâlpêtrière, describing it as *'a relationship of desires, gazes, and knowledge'*. (Didi-Huberman, 1982, tr 2003 p xi). He goes as far as to describe hysteria in the clinic as a spectacle, as *'the invention of hysteria'* covertly identifying itself *'with something like an art, close to theatre or painting'* (ibid p xi). However, Charcot's controversial practices brought photography right into the centre of research into medically unexplained symptoms. It is in the value of this role, but a questioning of his methodology which relate it to my work during **face2face** project. I hope the practices of Charcot, Duchenne and Diamond all provide historical counterpoints to my work, and serve to emphasise the contrast of our approach during **face2face**, underlining the importance of involving the subject in the practice of making photographic representations of their own illness experience.

### **Jean Martin Charcot: 'Founder of Modern Neurology'/'Napoleon of Neurosis'**

Interestingly Charcot had considered a career as an artist before applying to medical school and continued to draw throughout his life, both for pleasure and

for work (Hustvedt 2011 p 9). He drew when travelling, and when relaxing as well as when seeing patients - one of his students describing his drawings (while smoking hashish) in the following way: *'The entire page was covered with drawings: prodigious dragons, grimacing monsters, incoherent personages who were superimposed on each other, and who were intertwined and twisted in a fabulous whirlpool'* (cited Hustvedt p 9). Slightly disturbingly this does not sound so different from some of his and his colleagues drawings of females enacting potential poses during the stages of hysteria - equally entwined and twisted. In an essay *'Charcot artist, "Nouvelle Iconographie de la Salpêtrière" (1898)* one of his students Henry Meige considered Charcot's artistic perceptual abilities as contributing to his diagnostic abilities.

As with many practices in life, they have dual edges. There is something humane in Charcot's transformation of the notorious Salpêtrière Hospital from what he himself termed a *'grand asylum of human misery'* (Hustvedt 2011 p 12), an outdated hospital for epileptic, insane and ageing women into a modern teaching institution with laboratories and separate wards. There is equally something distinctly disturbing about his description of this transformed facility as giving him *'possession of a kind of museum of living pathology whose holdings are inexhaustible'* (Charcot 1880). It is perhaps this notion of ownership which seeps into his photographic portraits and which with a contemporary eye, we find particularly problematic. It is a notion that brings me back to my own work within hospitals and the questions of authorship and ownership it raises.

### **Charcot's desire for classification and his reservoir of human 'material'**

In keeping with his age, Charcot wanted to classify, to order and so understand the material he was working with (in this case female bodies plagued by psychiatric or neurological illnesses). He began by correlating clinical symptoms in the living patient with anatomical lesions found in his patients after death ((Hustvedt p 12). His meticulous observation, note taking and drawing from clinical evidence earned him a place as *'the founder of neurology'*, *'the Napoleon of Neuroses'* and greatly contributed to understanding of neurological diseases and to the birth of Neurology as a discipline. Freud described him as having *'the nature of an artist, ... a visuel, a man who sees.'* (Freud in Gray 1989, p 49). His desire to record and to classify extended more contentiously to



his desire to create a photographic record and to classify the physical signs and manifestations of what in that period was diagnosed as 'hysteria' in his female patients. Intersecting photography with all its claims to 'objectivity' and production of visual 'evidence', with the inevitable re-presentation of the sitter's more subjective notions of character and identity, and experience of illness, sets up much more of an ethical dilemma than using handwritten notes and drawings for the same purpose. It is how this dilemma is navigated, in fact in Charcot's apparent lack of awareness of there being a dilemma to navigate, which makes it relevant to this thesis. Charcot's methods produced photographs of the external observable manifestations and visible symptoms of a then medically unexplained condition: **face2face** in contrast attempts to involve the subject of the photograph in co-creating visual representations of internal and invisible sensations of a still largely medically unresolved condition. This is not to draw a parallel between hysteria and chronic pain; but to set up a contrast in methods of photographing the sensations and illness experiences of others in conditions where there are no visible physiological signs or lesions to explain their manifestation (difference perhaps between the culturally acceptable norms of the nineteenth and the twenty first centuries?).

To Charcot's credit, although he could find no physiological explanation, no lesion in the brains or spines at postmortem, he remained convinced that there was an organic basis for the disease, he just hadn't found it yet (Hustvedt 2011 p22). Perhaps we should apply a similar approach to the mysteries of chronic pain? Though two years after Charcot's death Freud claimed that hysterics were suffering not from a lesion in their nervous system but from repressed memories and ideas. (Hustvedt 2011 p 30 , ref 43). Has this paved the way for current explorations of the role of emotional processing in conditions with unexplained symptoms such as some chronic pain conditions, and the breakdown of the normal functioning of the pain system, such as discussed in chapter one?

Although Charcot was continually searching for a cause of hysteria he spoke little of looking for a cure, focusing instead on observing its trajectories and recording its stages through a number of visual means, drawings, re-enactments, casts and in particular, photographs. Despite the fact that it appears to be female patients he photographed and female patients who made their way into his public lectures and demonstrations, one of Charcot's legacies

was to break away from the argument that the cause of hysteria lay with the female reproductive system and to assert that hysteria could equally be found in men. He recommended separation of the word from its etymology, *'arguing that its Greek origin – uterus – should be abandoned.'* (Hustvedt 2011 p27). Why then is it photographs of his female patients which have made their way into medical history? An even more concerning question is why he continued to advocate the existence of *"hysterogenic zones"* and to employ the *"ovary compressor"*, *'an apparatus that was attached to the patient's abdomen and worked like a vice grip to apply pressure to the hysterogenic zone in order to elicit or suppress a hysterical attack'* (Hustvedt 2011 p 27)? Is this enjoyment of power over the female body, power to elicit a response for visual spectacle reflected in his photographs of women undergoing hysterical seizures and in his choice of female as opposed to male subjects?

In a pre-psychoanalytic age, according to Hustvedt, hysteria fell into a theoretical vacuum with the female body viewed as the site of a disturbing and incomprehensible split between its inside and outside (ibid 2011 p6). Interestingly Hustvedt also cites a new contemporary crop of illnesses affecting mostly young women which also resist biological explanation for example: anorexia, bulimia, self-mutilation, chronic fatigue syndrome, etc. Of these diseases she says: *'I believe that they may be read as a metaphor both for women's position in society and for the image of the feminine in the history of scientific discourses. Hysteria, that bizarre rupture between symptom and source played out on the female body has resurfaced in our post-Freudian era in new but oddly familiar forms'* (ibid p 8).

### ***Iconographie photographique de la Salpêtrière***

Charcot's idea was to use the women almost as specimens and find a designated professional who could photographically record the stages of their attacks of *grande hystérie*, (attacks parallel to but not identical with those of epilepsy), while they were underway. His defence of assigning an internal person specifically to make a photographic record of the visual appearance of hysterics was to address the problem, as he saw it, of the fact that by the time anyone was drafted in from outside the hospital to photograph an attack, it would be over (Bourneville 1876 -1877). He therefore initially commissioned

Paul Regnard (an intern at Salpêtrière) to photograph positions and expressions during the stages of hysteria, using the Salpêtrière patients. Charcot and Regnard, along with Bourneville, published details of this study, in a journal whose first edition, now renowned, in 1876/7 was entitled the '*Iconographie photographique de la Salpêtrière*.' It continued until 1880, resuming in 1888 under the title '*Nouvelle Iconographie de la Salpêtrière*' this time using images by Albert Londe, recently appointed by Charcot as the Salpêtrière's first Director of Photography, and reputed to be one of the great innovators of psychiatric photography (Gilman 1996, p 197). His photographs concentrate on the physical positions and sequence of positions during an attack. The *Iconographie* argued that the visual structures of hysteria paralleled other physiological illnesses, an argument further developed in his publication with Richer in 1889, '*The Deformed and Ill in Art and Medicine*' (Charcot & Richer 1889). Gilman calls the publication the '*most massive of all the art history studies produced at the Salpêtrière*' (Gilman 1996 p 200).

Looking at the photographs in the '*Iconographie*' gives me a very uneasy feeling (See fig 40). How much was the subject performing for her doctor and photographer? How much control did she have over the process or the end result, or the uses to which it was put, how much was she even conscious of these questions? In his study of visual representations of the insane, Gilman takes up this point describing Charcot's selected patients as particularly suggestible (Gilman 1996 p 200). Gilman questions whether they responded to what they had absorbed of Charcot's defined "correct" position for the stages of hysteria. He cites one of Charcot's favourite patients Blanche Wittman as an example <sup>8</sup>, as she was able to mirror the structured nature of hysterical episodes and the stages of hypnotic treatment which Charcot had identified (ibid p 202). Hustvedt hints at a similar complex relationship between doctor and patient, arguing that the Salpêtrière provided a '*language of hysteria*', which allowed the women '*to articulate their distress. Blanche, Augustine, and Genevieve mastered its vocabulary and were rewarded.*' (Hustvedt 2011 p 5)

### **Informed consent or exploitation?**

Contemporary notions of informed consent are a long way away from these photographs, but informed consent is a more ambiguous notion than it might

appear even now. I have full informed consent from the participants in the **face2face** project. They were given information leaflets detailing the process, discussed the rights, the uses to which the research and images would be put, they have signed consent forms, they have taken an active part in the photographs reflecting their pain and in the visual metaphors constructed in them, they have the right to remove any photograph from being shown in the public domain. But when one of the participants had an attack of TN, <sup>9</sup> a spasm which froze her face brought tears to her eyes and her fingers to massage her cheek, my reaction, knowing it was a rare event, was to photograph it. Was this an ethical response? I felt cold, callous, and as though I was invading a territory which was not mine. However, after the attack I showed her the photographs and we discussed how she felt about being photographed at a time of intense suffering and how she felt about my less than compassionate response, (and whether she wanted any of the photographs deleted). She responded by saying she was glad I took them as it is so difficult to get a photograph of the moment when an attack is happening, and she wanted it recorded for other people to witness. (However interestingly she also chose to have some of the images deleted - which we did there and then.)

How far away is this from Charcot's desire to have the moments of convulsion during hysteria recorded photographically before they passed? How far away is the co-creation of a language for pain, through which patients articulate their distress, from the language of hysteria which Hustvedt claims articulated the distress of those in the Sâlpêtrière? In my own defence, I feel the TN sufferer I worked with was involved in the decision of whether or not use the photograph and if so how - a courtesy which appears to have been denied the subjects of Charcot's photographs. The image of the attack the **face2face** participant wanted to retain has been used in some of her photographs for depicting the arc of her treatment journey. She wanted the portrait placed within a circle of polystyrene pierced by pins (pins were one of the objects she brought to the very first session and so hold personal significance). The circle is one of three polystyrene spheres hanging against a hospital background with different stages of treatment represented in each of three portraits, the last a smiling healthy face. See fig 42.

It represents something of her experience, her route to being pain free, but at the same time, for me, it represents a moment of shame, of shock at my own

response, at best a moment of self-questioning. I don't think the ethical dilemma was resolved, and I don't think it will ever be. Perhaps if it remains a question it will remain ethically negotiated. However it may be that successive generations will look at such photographs and wonder at the lack of compassion and consider the ethics problematic.

### **Dr G. B. Duchenne de Boulogne: Charcot's 'master of neurology'**

The disconnect between the emotions felt by some of the patients I have been working with and the emotions read into their facial expressions by others, parallels, while also countering, the work of Charcot's great mentor, the medical doctor and scientist Duchenne de Boulogne. Duchenne's interests focused on the separation of the mechanical functioning of muscles in the face from the experience of the emotions they expressed. Having practiced at the Salpêtrière, he was in many ways Charcot's mentor, Charcot calling him his 'master of neurology'. His photographic work recording facial expressions as a result of muscular contraction following the application of electrical stimulus, inspired Charcot's own photographic work. Duchenne himself wrote that his own careful study of isolated muscle action that it '*showed me the reason behind the lines, wrinkles, and folds of the moving face. These lines and folds are precise signs, which in their various combinations result in facial expression. Thus by proceeding from the expressive muscle to the spirit that set it in action, I have been able to study and discover the mechanism and laws of human facial expression.*' (Duchenne 1862a: (tr 1990), pp xv – xvi cited in Hamilton 2001, p 68). Through a twenty first century lens, Duchenne's portraits are as problematic as Charcot's. Looking at the photographs of his *Mecanisme de la Physionomie Humaine ou Analyse electro-physiologique de l'expression des passions*<sup>10</sup> in the Academie des Beaux Arts in Paris, I felt increasingly nauseous (Duchenne 2<sup>nd</sup> ed.1876, 1<sup>st</sup> ed. 1862b). Here was a face with electrodes prodding it, here the arms of Duchenne and his assistant holding the objects of apparent torture, here were shadows of those holding the instruments, there were the eyes of the subject, as far as I could see the only expressors of emotion within the image. The twisted grimaces, with the left or right side of the mouth or the eye brow raised or lowered, matched no expression I knew. In the eyes I saw only loneliness, resignation, sometimes

fear, sometimes pain. Perhaps this was my projection, but there was a stark chasm playing on my mind between the tender way in which these fragile photographic surfaces were held within the rich velvet wrappings they are viewed in, the carefully preserved archival boxes they are stored in and the harsh treatment of the faces they depicted, the skin probed by electric rods, - no such gentle caresses accorded them. Their effect was dramatised by the use of light and shadow, reflecting a sense of theatre or performance, also commented on by historian Peter Hamilton (Hamilton p 62), leaving me to feel that my response was not purely personal projection, it might also have been manipulated. It also links these works with the theatricality of Charcot's photographic 'records' of hysteria. See figs 43, 44, 45 , 46 and 47.

The first day I visited the library at the Ecole Nationale Supérieure des Beaux-Arts where they are stored, I was only allowed to see five because they were *tres fragile*. How much attention was paid to the fragility of the sitter, the instability of identity, the vulnerability of his mental well being? The second day for some reason, still unknown to me, I arrived to be met by piles of archival boxes housing their precious treasures. I wore the protective gloves I had brought and under the watchful eyes of the librarians was allowed to leaf through and photograph. The photographic skin was stretched on material across oval wooden frames, some of the sepia toned surfaces were cracked, adding a viscosity to the experience, but more evident than anything was the growing feeling of nausea and repulsion that overtook me as I viewed one image after another of a face contorted by electrical stimulus. The captions read '*douleur*', '*grande douleur*' etc.

Duchenne was trying to demonstrate the physiological basis of expression. In fact his '*Mécanisme de la physionomie*' was claimed as the first scientific work to use photographic portraiture as an integral element of a proposed theory (Hamilton 2001 p 57). It was also the first study of the physiology of emotion, preceding Darwin's later influential work on the expression of human emotions.

<sup>11</sup> His publication '*Le Mécanisme de la physionomie humaine, ou analyse electrophysiology de l'expression des passions applicable a la pratique des arts plastiques*' (The mechanism of human physiognomy, or electro-physiological analysis of the expression of passions, applicable to the practice of the plastic arts) was published in 1862, is a collection of 74 photographic portraits capturing electrically induced facial expressions linked directly to accompanying scientific

texts. He gives an account of the fact that he took most of the photographs himself: *'For my research, it was necessary to know how to put each expressive line into relief by a skilful play of light. This skill was beyond the most dextrous artist; he did not understand the physiological facts I was trying to demonstrate. Thus I needed to initiate myself into the art of photography. ... I photographed most of the seventy-three plates that make up the Scientific Section of this Album myself, or presided over their execution.'* (Duchenne 1862 b: 1990 p 39), but in various documents pays tribute to the skills of and assistance he had from the portrait photographer Adrien Tournachon. There were several versions of the first publication, but each consisted of text pages to which separate photographic prints on salted or albumen paper were added (varnished and pasted onto card). Some volumes were bound and some unbound so that they would be easier to use in situations such as a studio or laboratory. There were also 'de luxe' quarto editions including between seventy four and eighty four plates – contact prints from the 18 x 24 glass plates the photographs had been made from. (Hamilton pp 65 -8).

Ironically, there is again a comparison with my own collaborations with the pain sufferers I work with. For them there is a schism between the emotions felt and the emotions read by others as their facial muscles freeze in pain rather than contracting in the expected manner. The canvas normally used to express pain is unable to do so because it is itself in pain. There is therefore an interesting if uncomfortable correlation and contrast with the work of Duchenne. There is also a parallel with Duchenne's perception of photography as both an art and a science. He was one of the earliest exponents of photographic practice to integrate disciplines, working within both medical and arts arenas. He not only recorded his experimental investigations of facial expression for the benefit of medicine and medical students, but used them in the training of art students at the Ecole des Beaux-Arts to train painters in what he described as the 'accurate' depiction of emotion through facial expression. He wrote in his preface to the *'Mecanisme de la physionomie humaine'*: *'Using photography I will illustrate the expressive lines of the face during electrical contraction of its muscles. In short, through electrophysiological analysis and with the aid of photography, I will demonstrate the art of correctly portraying the expressive lines of the human face, which I shall call the orthography of facial expression in movement'*. (Duchenne 1862 b cited Hamilton 2001). At its inception photography was perceived as belonging to the terrain of science, Duchenne

was well ahead of his period in being fascinated with transposing conventions from scientific to artistic domains and vice versa, to create new knowledge. He even appended an aesthetic section 'partie aesthetique' to his *Mecanisme*. In this he claimed to '*show a sample of what could be obtained in the realm of art and beauty, using my physiological experiments on human facial expression*'. (Duchenne 1862 b in Hamilton 2001 p 65). These images are '*far from neutral scientific records*' (Hamilton 2001 p 61), taking some of their inspiration from Shakespeare! '*Lady Macbeth – receiving King Duncan with perfidious smile. False smile on the left, by covering the right side of the mouth. Feeble electrical contraction of the left m.zygomaticus major at the time when the face expressed malcontentment.*' (See fig 47, Duchenne 1862 b in Hamilton 2001, p55). Duchenne's own justification of this photograph problematises not only its construction as 'evidence' but its interpretation as 'evidence' dependent on the inevitable presumptions and prejudices influenced by the cultural and historic norms of the viewer. '*... The left side thus displays a delightful expression of rapture reminiscent of the ecstasies of St. Theresia. At this point I made the muscle of lasciviousness ... on the right contract lightly, and then the expression on this side alone assumed a charming character of sensual pleasure more evident after the left side is covered. ... we sense that it is not only the result of the delights of divine love but that the memory of her loved one exalts her imagination and her sense. This is the ideal poetry of human love.*' (Duchenne 1862 b in Cuthbertson (tr) 1990 pp 110-11).

As the century proceeded, photography became caught up with the dominant social and political as well as scientific ideas further cementing the link between knowledge and sight established during the Enlightenment. The resultant fascination with phrenology and physiognomy entered not only medical but also studio portraiture and anthropological records. '*The growing systematisation of photographic documentation of the human face during the nineteenth century 'feeds back' into social portraiture, with the latter used to present ideal types of European Society against which each family or individual could compare themselves*' (Hamilton 2001 p 63). Photography, therefore, begins to contribute to a construct of normal and abnormal, for which it became an overt vehicle in the attempted visual classification of 'criminal' or 'insane' types. In contrast to Duchenne's work as a male authority figure experimenting on, classifying and objectifying his subjects, my own portraiture attempts to collaborate with patients who remain in control of how their experience is visualised, taking portraits



"with" and not "of" them. I hope this reflects more contemporary notions of portraiture and ethical issues around the representation of others, which have evolved in the intervening period since Duchenne and Charcot. However, albeit from a different standpoint, my work attempts to probe the disconnect, when it exists, (for example during a TN attack) between emotion and facial expression. There remains an interesting relationship to Duchenne's work even though I might want to distance myself from it. Against this it is important to state that I am not working with the insane, the destitute or the incarcerated. The people I work with are functioning in the community in a variety of occupations and opt to take part for a variety of reasons, but financial need and coercion are not amongst them. It is made very clear from the outset that participants will receive no financial gain from taking part and their medical care will not in any way be compromised or enhanced (see consent forms in appendices pp i, ii, and iii). This is a crucial element to highlight. Most of the clinicians and scientists who grasped the new possibilities for observation and evidence gathering that photography offered in the nineteenth century, experimented with groups of people typically without a voice. The 'poor', the 'insane', the 'hysterical', the 'demented', the 'criminal' were all groups who had little access to power, who were dependent on the institutions they were confined in, and whose decisions to participate (if indeed they were consulted at all) were influenced by the situations of need they found themselves in and not arrived at through dialogue and consent negotiated within equal relationships.

### **Dr Hugh Welch Diamond**

A similar pattern existed in the ways the new technology of photography as a 'scientific' tool was seized on and applied by Science in England as much as France. Within medicine, it was predominantly used to study the facial appearances and bodily poses of mental patients in asylums. Photography, according to Hamilton, emerged at exactly the point where science and medicine were focussing upon the insane and trying to construct typologies for 'diagnosis, treatment and control' (Hamilton 2001 p 79). The same combination of the medical and photographic gaze evident in Charcot's work was present, again predominantly sweeping over the female bodies of the sick and infirm. It is impossible to keep the inequality of the power dynamics within these photographic exchanges out of any discussion of their methods. Developing

within the context of a fascination with classification and a desire for social ordering, for which the Victorians were renowned, the use of photography to classify psychiatric conditions is a prime example of those at the most powerful end of the social hierarchy abusing an unhealthy amount of power over those at the bottom. In fact, Peter Hamilton identifies a disturbing equivalence between the ways doctors photographed mental patients and the ways anthropologists and colonial administrators photographed the 'native' people under their control (Hamilton 2001 p 61). However, it might be wise (in an age of increasing distance between the wealthy and the less wealthy, the powerful and the less powerful) to continue critiquing these methods in order to have an understanding with which to critique our own new methods of medical visualisation and advancement of new theories as they emerge. It might be that similar inequalities of power appear in unexpected places where we may not recognise them, under the names of perfectly well intentioned euphemisms such as 'barrier nursing', 'patient centred care', or Tracey's fMRI 'readouts' of the pain experience, aimed to evidence the likelihood of the pain having a mechanical or psychosocial cause (Tracey 2005, p 137).<sup>12</sup>

Like his French counterparts, psychiatrist Dr Hugh Welch Diamond (Superintendent of the Surrey County Asylum, Twickenham) was not only a leading figure in research into psychiatric conditions but also a keen photographer. With Roger Fenton, he co-founded the 'new Photographic Society' in 1853 '*to promote the Art and Science of Photography*', which, in 1894, became the 'Royal Photographic Society'. Diamond was a leading figure in the new treatment-centred psychiatry of the 1850's and 60's (Hamilton 2001 p79). Having trained as a psychiatrist at Bethlem Hospital, he took up a post as resident superintendent of the Female Department of the Surrey County Lunatic Asylum, beginning his project using photography as a treatment process with the women's section in 1852. He remained there until 1858. Like Charcot, he had a humanising effect on the ethos of the asylum, being a noted exponent of 'non restraint'. He was also associated with a shift in psychiatry towards thinking of mental health sufferers as 'mental patients' rather than 'lunatics'<sup>13</sup> (Hamilton 2001 p 79). Countering this is the fact that, like Charcot, his photographic experiments into the potential of photography as a treatment and diagnostic process were carried out within the women's section of the hospital (see fig 41). This not only highlights the role of women in his day but the acquisition of photography by a dominant group in the objectification of a less

dominant. It is the latter that as photographers we need to bear in mind, particularly when working in a medical environment. How can the relationship be equalised, how can a subject not be objectified but become part of the process, how are we obtaining consent, how is the environment the exchange takes place in affecting the encounter and what is the contract?

The beginnings of photography's use in medicine by amateurs started almost with the beginnings of photography itself, for example there were even early experiments to record breath patterns exploring pathologies of the lungs, and much later in 1895 the renowned photographer Edward Muybridge explored the use of sequential chronophotography to document neurological cases.<sup>14</sup> However, Dr Hugh Welsch Diamond is heralded as the first to apply a systematic approach to the use of photography within psychiatric medicine. In 1856, he presented his findings to the Royal Society in his paper "*On the Application of Photography to the Physiognomic and Mental Phenomena of Insanity.*" ( Gilman 1996 p 164).<sup>15</sup> A summary of the paper appeared in the *Saturday Review* 2 (1856), 81 and was reprinted in *The Photographic Journal* 3 (1856) 88 -89. Diamond's use of photography with those with mental health conditions was multifaceted. He identified three main uses or aims for his photographs, all of which could be challenged:

- 1) The first was to record the appearances of the mentally ill for research and the acquisition of knowledge - making (what is now highly problematic) a direct link between the facial appearance of a person and his or her internal state and pathology. He argued that photography could record "*with unerring accuracy the external phenomena or each passion, as the really certain indication of internal derangement, and [it] exhibits to the eye the well known sympathy which exists between the diseased brain, the organs and features of the body.*"(Diamond 1856, cited 1996 Gilman p 164).
- 2) The second was photography's use as a treatment through the presentation to the patient of an 'accurate' self image. As the 'self-image' was created by the doctor, the concept of 'accuracy' is also highly questionable. "*There is another point of view in which the value of portraits of the Insane is peculiarly marked. – viz in the effect which they produce upon the patients themselves – I have had many opportunities*

*of witnessing this effect – In very many cases they are examined with much pleasure and interest, but more particularly in those which mark the progress and cure of a severe attack of Mental Aberration...*

(Diamond 1856, cited Gilman p 164).

- 3) The third was to facilitate identification and recognition in cases of re-admission. There is even mention of its potential benefit in relation to the 'criminally insane' for assisting the police with identification and capture, further linking criminality with mental ill health or deviance from 'normal' behaviour: *"the portraits of the insane ... give to the eye so clear a representation of their case that on their re-admission after temporary absence and cure, I have found the portrait of more value in calling to mind the case and treatment, than any verbal description I may have placed on record"* (Diamond 1856, cited Gilman page 165).

When I read through the uses to which Diamond geared his photography again I feel uneasy, not just because of the obvious problematics illustrated in the work, but because of niggling questions it raises in relation to my own practice. Gilman cites T. N. Brushfield (Medical Superintendent of the Chester County Lunatic Asylum) as stating:

*I have not had an opportunity of reading or knowing the contents of Dr Diamond's paper on photography as applied in the treatment, &c. of lunacy, beyond the ordinary newspaper article; but I have found, notwithstanding my imperfect attempts, that patients are very much gratified at seeing their own portraits, and more particularly when associated with a number of others on a large sheet of Bristol board, framed, and hung up as an ordinary picture in the ward."* (Brushfield, 1857, p 289 cited in Gilman 1996 p 166).

### **Staging and honesty of the exchange**

This poses questions around what is the subject, in this case the patient, getting from the exchange. Is there a sense in which they become 'star' patients, through which they achieve identity and acceptance through the mediation not only of photographic processes but through their treating

doctors and thus change their status within their cohort, as well as in relation to their doctor? Didi-Huberman identifies photography's ability to crystallize a link between the fantasy of hysteria and the fantasy of knowledge, describing a '*reciprocity of charm*' instituted '*between physicians, with their insatiable desire for images of Hysteria, and hysterics, who willingly participated and actually raised the stakes through their increasingly theatricalized bodies.*' (Didi-Huberman 1982 tr 2003 p xi). One of the aims of the **face2face** project is to print and display photographs from the study in patient waiting areas to encourage and inform new patients. However, in doing this are those patients being presented as 'special' in some way, set apart from the rest? Are future patients burdened with an expectation to match up to these 'hopeful' narratives? Are the patients whose narratives are on display being exploited in any way in order to present the successful face of pain management? These are not easy questions when the process and practice is well intentioned. However the practices of Charcot, Duchenne and Diamond were also well intentioned, also produced benefits for later clinicians and patients, but their methods remain problematic. Presumably, so too do ours, despite our best intentions. Attention to self-image was exhibited by patients requesting Diamond that they be photographed with different props, suggesting awareness of the construction of identity through the photograph. Gilman identifies a description of a patient's reaction to her portrait by Sir William Charles Hood at Bethlem Hospital in the early 1850's where she made it a condition of her sitting that she held a book in her hands "*The book, indeed was held upside down; but it did quite as well. Her sense of propriety was gratified, and her face shows that she required no printed page to suggest thoughts to her yet busy mind*" (cited Gilman 1996 p166). Both the subject, in her request for props representing a perceived propriety, and the clinician in his interpretation of her expression as illustrating a mind too busy to need the contents of the printed page, exhibit the prejudices and presumptions of the day, rather than any evidential truths about her condition.

### **Pressure to 'perform' or enact identity projected by others**

I also wonder about the 'identities' my own portraits have constructed. I believe I have constructed them with the people I work with, but they

probably also represent aspects those people are willing to present to others, and almost inevitably will privilege one facet over others of multifaceted lives and personalities.<sup>16</sup> I have greater fears about the use of the images to represent the arc of a journey through treatment. It is almost impossible to discard a wish to make visible positive changes that pain sufferers have made in their perceptions or experience of pain. That in itself is an external imposition or pressure put on the evolution of the photographs, and parallels Diamond's reflections on the value of patients witnessing the "*the progress and cure of a severe attack*". Diamond is talking of those with mental illness and consequent reduction in capacity to fully consent, but even when working with the mentally well how much unacknowledged pressure is there to present their own cycle of images as following a positive arc, as deserving of or justifying in some way the medical treatment and attention they are receiving, to warrant future treatment if they relapse? I am reminded how incredibly important it is to leave space for the visualisation of experience and journeys which do not follow such anticipated arcs from debilitating to less debilitating pain, to allow space for more difficult and ambiguous experience to be reflected and acknowledged, for the pain cycle to be visualised as an ever continuing spiral, when and where that is what is experienced by the sufferer. The complexities of the pain experience can never be captured in a single series of images, we have to remember the limitations of photography while attempting to harness its potential to bring into visibility something, however slight, of another's experience of suffering and pain. Even with these reservations, overall the benefits of reflecting changes patients have made, might outweigh potential dangers. For example at the end of the process, one of the **face2face** participants stated:

*I couldn't see anything other than being stuck in that pain cycle ... I was locked in a place with this pain and couldn't move forward. I think through coming here and having a look at a beginning, a middle and an end, it somehow moved me onto the next phase and psychologically I could look at it differently. I don't know, without this, how I would have moved.'* (participating patient Study no I3).

The Medical Director of Chester County Asylum, T.N. Brushfield, discussed earlier, a keen advocate of photography within medicine, goes on to assert that

photographic portraits of the *'insane'* were particularly useful as so many of them were of *'criminal disposition'*, further sealing photography's future fate as a surveillance tool and re-enforcing the perceived link between facial appearance and character or identity. To quote John Tagg, there was a disturbing move towards the combination of an: *'ever more intimate observation and an ever more subtle control: an ever more refined institutional order and an ever ore encompassing discourse: an ever more passive subjection and an ever more dominant benevolent gaze'* (Tagg 1980 pp 17 - 55).

The photograph provides a certainty that the named or unnamed person was there when the photograph was taken, but it provides no other certainty, no definition of identity or character, no 'proof' on which we can rely. It is along this liminal tight rope between certainty and uncertainty, authenticity and falsification, truth and fantasy, that much of photography's attractiveness for artists lies. When the artist's practice is also situated within an arena where a great deal is at stake for the subject, for example the medical or judicial system, it needs to proceed with great caution and self-interrogation.

### **Photographs as a means of eliciting narrative: photo-elicitation, photo-therapy, photo-voice**

Before moving onto discussing contemporary artists, whose practice it could be said undermines these historical uses of photography in medicine, it is worth looking briefly at other ways in which the photographic surface has been used by the social sciences to elicit narrative; sometimes called photoelicitation. This has been continually expanded on and developed by techniques such as Jo Spence's *phototherapy* (Martin 1987, Spence 1986), *photo-voice* (Wang et al. 1996), and studies such as those by Thoutenhoofd (1998) which explore deaf people's worlds through photographs, terming the process *autophotography*. The University of East London is a known centre for research into narrative methodologies, notably Barbara Harrison who has written an excellent overview of the ways in which images have been used within sociology and medicine (Harrison 2002). Harrison analyses a range of studies which use different visual media to capture narrative, broadly within the sociology of health. She *'highlights the value of visual methodology projects within qualitative*

*approaches to research more generally, and assess the difficulties as well as the advantages'* (Harrison 2002 b p856).

Social Psychologist Professor Alan Radley (Loughborough) has also long been an advocate of the use of photography to explore illness experience to make suffering communicable to others, sometimes to achieve direct social action. In his recent volume *'Works of Illness'*, Radley (2009) explores a key question – *'can one evaluate the role of stories (narratives) and pictures (visual material) in the same way? Are they indeed separable, or do they trade on one another in ways that require some unifying conceptual framework?'* (Radley 2009 p 13).

This relates very much to my own exploration of the interdependency of text and image, referenced at the end of chapter one, and the ways in which each can enhance and modify the other. I believe narrative is not only communicable through verbal stories, it comes into being through images as much as it does through words. However, my initial belief that we could create a visual language for pain independent of verbal language, has been modified during the process of this research and I now believe it is the impact of images on dialogue and the inter-relationship with language effected, rather than the images themselves, which form the richest routes of enquiry. Of Radley's latest exploration of the value of images to communicate the experience of those with serious illness, Professor of Medicine & the Arts at Kings College London, Brian Hurwitz writes: *'Radley deftly brings sociological, aesthetic and philosophical approaches together in a sustained analysis that deepens and strengthens our appreciation and understanding of the many faces of serious illness.'* (Hurwitz B in Radley 2009). Rita Charon, Professor of Clinical Medicine Columbia University New York and advocate of narrative medicine declares the: *'breathtaking range of this pioneering book reaches and therefore unifies social science, phenomenology, aesthetics, literary art, and suffering 'borne'* (Charon in Radley 2009). Radley's own research projects from the 1990's onwards have used photography in a variety of ways giving cameras to people who found themselves homeless, or people in hospital wards, or returning home from hospital and using these photographs to elicit narrative and thereby increased understanding by others of their experiences. However, generally as far as I know, his is an analysis of images made by ill people, with none of the images, as far as I know, taken by or co-created with professional photographers.



## PHOTOGRAPHY AND PAIN IN FINE ART

In the twentieth century, early uses of photography within medicine were replaced by practices which undermine those now disputed approaches to photography in a clinical setting of their predecessors. Photographers became far more conscious of the levels of control and objectification evident in the work of their nineteenth century counterparts, particularly in early psychiatric photography. Greater awareness of the exchange and transaction between photographer and subject evolved with attention now paid to the ethical concerns of imaging patients and the notion of informed consent, with practices to preserve the dignity of the patient/subject such as the slightly contentious black eye bands. Arts in health practices began to grow into the expanding arts and health sector which exists today. The fact that the work of so many skilled artists now intersects with science and medicine, for example: Annie Cattrell, Andrew Carnie, Suzanne Anker, Luke Jerram, Chris Drury, Christine Borland, Katherine Yass, Helen Sear, Alexa Wright, Stephen Dwoskin, Gina Glover and Karen Ingham to name but a few, has impacted on the quality of work in the area and the sophistication of the developing photography/medicine and fine art/medical discourses. For example, work in the recent '*Experiments*' exhibition, GV Art, 2010 such as Annie Cotterrell's *pain/pleasure*, Chris Drury's *Life in the field of Death*, Anne Brodie's *Basement Series*, Andrew Carnie's *Seized* and Katherine Dowson's *Micro Macro 4*, 2010, all focus public attention on, and bring new awareness to, areas of medical interest without losing any of their strength as works of art. The same could also be said of Susan Aldworth's new series of prints etched directly from brain tissue, a collaboration with Professor David Dexter, Scientific Director of the Parkinson's UK Brain Bank, currently on show at GV art in London, July 2013. It is with this type of work, where the interaction with medicine or medical practitioners is integral to the process and artistic outcome but without the artistic practice being either illustrative or becoming a servant of medicine, that I would like my work to be positioned and have a dialogue.

## Jo Spence: phototherapy and *transformation*

The evolution of clinical photography has been little studied (Gilman 1996 p14), however a key pivotal figure in this transition from a controlling to a more shared gaze via photography and control of the lens, was Jo Spence. Spence developed a means by which the person with pain/illness could remain in control when subjective notions of physical or emotional pain or illness were being visualised, through a technique developed with photographer Rosy Martin, which they called 'phototherapy'. Phototherapy avoids the pitfalls of tension between a controlling gaze and a vulnerable subject as it unites both within the same entity. Here the person whose experience is being explored directs the gaze of the camera, directs the person behind the lens.

It was a natural development of Spence's auto-therapeutic strategies, described earlier in the chapter, swapping herself in the role of therapist for a trusted partner/photographer taking the role of therapist. It was a result of Spence and Martin's joint interest in deconstructing the mythologies of the photographic gaze, such as the concept of a decisive or perfect moment, the 'truth' of the photographed image. It was another way of interrogating notions of 'truth' or 'fixity' mediated via photography and worked to '*expose the image production processes, working against the grain of existing mythologies*' (Martin in Spence 1986, p 175).

The technique was a '*reframing*' technique which Spence described as a way of being given permission to change, to re-view, to let go, a way of '*finding new ways of perceiving the past so that we can change our attitudes and activities.*' (Spence 1988 p 172). It consisted of acting out aspects of the self and exploring these through re-enactment in front of a camera followed by re-view of the photographs with the photographer/therapist. The aim of the process was *transformation*. Spence asserts that '*using reframing as a technique anything can potentially be turned on its axis, words and images can take on new and different meanings and relationships and old ideas can be transformed*' (Spence 1988 p 173). In **face2face** the photographs are not seen as a way of transforming experience necessarily, but of eliciting memory and discussion which themselves can be transformative processes. The process of working with pain sufferers at different points in their treatment/management journey

could be seen either as transformative itself or as a means of evidencing transformations patients have made themselves in their perception.

How much the photographs are re-enactments allowing review of a perception or how much they are documenting transformations which have occurred and providing triggers or jump off points from which to begin discussion, is an open question.

In her Workbook notes (Spence 1982 cited Dennett 2011), Spence observes:

*The photograph should serve as a jumping off point to direct us to real life situations existing outside the photographic frame. Our photographs should present the viewer with questions, the work we do will only have a final 'reality' effect when it functions as an arena for discussion and more importantly acts as a call to action'. (Dennett 2011 p 235).*

Photographs, like pain, demand action, and when these work together to produce transformation it can be very powerful.

What my own co-creation practice and photo-therapy share is the inclusion of the subject, the person with the pain or illness in the process of taking the photograph, in the photographic re-presentation of their pain/illness experience. It is this exchange between photographer and subject, patient and clinician, and artist and clinician which intrigues me. Although my practice has many overlaps with art therapy, and indeed with phototherapy, I see my collaborative practice with pain sufferers, instead of therapy, as an essential component of my artistic practice. I attempt to photograph and make visible other people's subjective experiences and therefore those other people need to intervene in and influence the creation of the visual outcome/art object. I would like to expand the boundaries of fine art practice to be able to accommodate this type of process.

### **Steve Dwoskin and Bob Flanagan: *pain as pleasure***

The problematic nature of co-creation in relation to pain was picked up on by film-maker Stephen Dwoskin in an interview he gave me in 2002. He had just finished working on a short film '*pain is ...*' to be shown at St Thomas' Hospital,

initially within the ***perceptions of pain*** exhibition in July 2002. Discussing my collaboration with Dr Charles Pither and patients from INPUT, I told him of our ambitions to create a visual language for pain with pain sufferers. His first response was:

*I may be wrong, but in terms of dealing with your pain yourself, it is the actual act of doing things to your body outside your body. A picture can only trigger what things you can do. You have to establish, a language and a vocabulary to express your pain, and maybe you can do that with a photograph, individual people might find other vehicles, I don't know if you can make an object for other people (Dwoskin, 2002)*

The exchange continued:

DP: *But if they have set the photograph up themselves, isn't that them finding the language, and it has just been informed by me coming along and taking the picture but they have set it up – it is their language? Each photograph is going to be different so what I am hoping is that I end up with a series of photographs which do begin to form a language for pain.*

SD: *I don't know. I don't think it has been done, but you will have to find out. When I made the film [pain is ...] I found out that actually there were very few things image wise that can get the sense of pain. Some obvious things can in an intellectual way, but in terms of the emotion of pain, and giving people something to focus on it almost works in opposition to what you are doing.*

This exchange was shaped by the fact that at that point my co-creation process was still forming and two things seem apparent to me with hindsight; the first is that I appeared to still be seeing the photographs as created by the patients without much aesthetic input from me, almost viewing myself as a mechanic under their direction; secondly, I had not acknowledged my inevitable role in any of the aesthetic evolution of the images, and thus the representation of the pain of others – and I had not fully interrogated the many levels in which I was involved in a co- construction of their pain narrative through my role as what an anthropologist would term 'participant observer'.

The conversations I had with pain sufferers during the 1:1 sessions inevitably affected the images developing out of them; the ways in which we worked together impacted on the types of images that evolved and the facets of pain experience privileged within them; the aesthetic decisions I could not help making (albeit in dialogue with the sufferer) could not but direct the aesthetics of the final images - in other words the pain narrative as well as the visual narrative was not just being witnessed but being constructed during the process. It was to be further co-constructed when the images were reviewed later with health professionals in a medical setting.

The interview with Dwoskin was also shaped by the fact that Steve's film and much of his work in relation to pain and illness explores pain via the body and specifically through aspects of S & M. Pain is thus re-contextualised by him, re-framed through the lens of pleasure substituting ecstasy for suffering - re-interpreting intense physical sensation as controllable elation rather than pain.

When Dwoskin was speaking of performance artist Bob Flanagan's work, he could be describing aspects of his own:

*putting his body through what appears to be painful physically outside which he could control, isn't actually painful. Instead of the internal pain which he couldn't control he is refocusing his pain into something he could deal with. It is really gaining control of yourself through the process of pain, to have some tangible way of dealing with it. ... the pain which is really uncontrollable is chronic pain, where you can't see it, and it gets confused with how you think about things. ... You can't get inside your body, so Flanagan dealt with the outside of his body as a way of externalising and controlling the pain, basically refocusing his sensations into focusable thing. (Dwoskin, 2002).*

Flanagan had cystic fibrosis and collaborated with his partner, Sheree Rose, on installations, poetry, videos, and performance, positioned on the borders of public and private realms, using eroticism in the way Dwoskin intimated to transform inner painful experience, expose it to a public gaze, whilst all importantly, remaining in *control* of it.

The emphasis most pain sufferers put on the need to remain in control has been

evident throughout both **perceptions of pain** and **face2face**. In the film **duet for pain**, Ozarovsky voices it clearly: *'That I am not at all in control of the pain in my neck is totally a disaster'* (Ozarovsky in **duet for pain**, Padfield, 2012).

Petra Kuppers (academic and community artist) describes sadomasochistic performance practice as enacted by Dwoskin and Flanagan as a discourse of private and public experience articulated via pain and the body, seeing them: *'as the creation of a density, a black hole that incites the gaze but denies closure'* challenging rhetoric's of sentimentality and sympathy (Kuppers P. 2007 p 78). In this thesis I am not researching disability and its representation nor am I looking at pain and pleasure, but more specifically at pain and its consequent suffering, exploring the potential benefits arts practice can offer clinical practice. However, like beauty and ugliness, seduction and abjection, pain and pleasure are sometimes only fully known through their opposites.<sup>18</sup> Framing the use of sado masochistic practices whether raw personal experience or experience transformed through performance practice as a way of having control over inner uncontrollable pain helps me understand, for example, the self-harming practices of one of the pain sufferers I worked with. She claimed that cutting herself *'was the only way I could express it [pain] at the time. In order to make scars like that you have to concentrate quite hard so it takes away from the pain that is there all the time.'* (Lowe in Padfield, 2003 p 41).

### **The bound or restricted body – phenomenology of pain**

Dwoskin reflects that: *'The biggest symbol of pain is Christ. It has been made as a focus for people in pain to go through. It is a bit like the beads people keep rubbing, or pinching yourself to see if you are alive. In pain you have to get outside yourself.'* (Dwoskin interview 2002). The significance of the body being bound is particularly poignant in relation to bodies whose movement is restricted already through illness, pain or disability. For me it generates flashbacks to the disturbing images I saw in the Bertillon archives in the Paris Police Museum, where murder victims were tied up or restrained. What Dwoskin's statements emphasise is a phenomenology of pain - that pain is experienced with and through the body. Dwoskin continued describing pain as: *'the embodiment of all the sensations we have, the amount of pain we have is how we deal with sensation in general, eg how we deal with the pleasure or displeasure of colour'*.

(Dwoskin interview 2002). His remarks remind us that pain, though processed in the brain, is experienced through the body. Academic and cerebral palsy sufferer Minae Inahara's attempt to reconceptualise pain as something that can be captured in embodied expression, countering some of the claims to pain's inexpressibility and unsharability voiced by Scarry (1985) and Morris (Morris 1996 pp 131 -2) is brought to mind.

Inahara uses the writings of Wittgenstein (1953) and Kristeva (1986) to support her argument, as well as examples of some of my own photographic images from *perceptions of pain*, where the materiality of the photograph is effectively standing in for the body (Inahara 2012). The body cannot be marginalised from any meaningful discussion of pain or arts practice and pain. Amelia Jones observes that: *'While pain cannot be shared, its effects can be projected onto others such that they become the site of suffering ... and the original sufferer can attain some semblance of self-containment (paradoxically, through the very penetration and violation of the body'* (Jones 1998 p 230).

This parallels Dwoskin's awareness of the different effect the image or performance has on each viewer, and the schism in some of these more disturbing art practices between the experience for the artist/maker/performer and the viewer. *'Pain is very personal, for example if you have someone being whipped and you make a picture of someone being whipped, ... , the person being whipped is not feeling pain, but the viewer sees it as being painful, ... The pain is the viewers' and not the participants'*. (Dwoskin interview 2002).

Dwoskin's comments highlight the role of interpretation, not just of the image but of pain itself. These thoughts echo those of pain specialist, Dr Charles Pither who talks of the significance of the pain for an individual, and his belief that this can prolong and intensify pain experience. (Personal communication 2001-06).

### **A phenomenology of subjectivity, subjectivity inscribed within the body: Grosz**

There is an inevitable relationship between the psyche and body within pain processing, perhaps best conceptualised through Grosz's re-conceptualisation of subjectivity as inscribed within the body. Both the psyche and the body

encounter the events of our lives and have its narrative inscribed on them. In describing the ways in which our bodies are embedded within social systems that create the framing for both pain and imagination, Academic Petra Kuppers cites Scarry's understanding of work and creation as basic functions of humanity (Kuppers 2007 p 77). In Kupper's words: '*people transcend their bodies, they body forth an object; re-moving themselves from pain, they extend themselves into the world.*' (ibid p 77). The passage from Scarry's seminal work which Kuppers selects raises questions for me in relation to pain's intensification not only through the alienation of isolation discussed in chapter one but conversely through the alienation of involvement in work or activity which is itself alienating.

*The proximity of work to pain is here specifically attributed to the massive hunger, sores, disease, airlessness, and exhaustion suffered by the industrious population, but all these conditions are in turn attributed to the more fundamental shattering of the essential integrity of act-and-object in the human psyche; for the body at work was separated from the objects of its work' (Scarry 1985 p 170).*

Although Scarry was citing extreme forms of labour such as slavery in ancient Egypt and the US or factory conditions of nineteenth century Britain, her observations are relevant to contemporary discussions on pain, pain narratives and the impact of pain generally. When I think of the people I have either worked with who experience chronic pain, or those who attended the pain management programme with me at INPUT, there are very few I can identify who returned to the same work they were doing before the onset of pain. This is partly due to the limits pain puts on mobility, and the real ways in which pain inhibits capacity to carry out normal work, particularly when it is manually/physically demanding. However it makes me wonder if some of the tensions of previous work, stress, unhappiness, lack of satisfaction or ownership of its production also create an alienation which plays a part in pain's complex processing system.

### **Making sense of pain: re-making a coherent sense of self**

The alienation may not have to be alienation or isolation from others, as in the Eisenberger study referenced in chapter one (2003), but alienation from the self.



Professor Christopher Eccleston argues that people need to be helped to make sense of what it is that is overwhelming them, and to understand what it means to be them in the world (Eccleston 2012). Making sense of and healing pain is perhaps a process of re-making a coherent sense of self. I include myself in this query. I had spent eight years in the theatre, which initially I missed intensely - there is nothing like the adrenaline and spontaneity of live performance, but I wonder if I am more suited to the work I am doing now than the life of the theatre. I wonder how much the stresses of auditions and theatre life played into my own pain response. Equally, I wonder how much the fusion of work and creativity, both of which Scarry argues are basic functions of humanity, has played a role in my own healing process. I have been very lucky in that my employment, my means of earning an income now collides with my mode of creativity and self-expression - the means my subjectivity has found of interacting with the external world. The creative process has become my means of reflecting on my own pain experience as well as that of others and through it I have gained understanding of my own pain. I feel particularly lucky that the opportunities I have been offered have meant that for me productive employment and creativity have become one. I do wonder what happens for those who are not offered such opportunities however much they would grasp at them if they were.

### **Alexa Wright: disruptions to the self, phantom limb pain**

Issues of perception and pain, ways in which the mind can be tricked rather than consciously control through re-interpretation, as in Dwoskin's work, feature prominently in the work of lens based artist Alexa Wright. In the 1990's, Wright was photographing surgical procedures, in her words observing '*what happens when the surface of the self is disrupted*' (Wright in Roberts p 68). During this period she became intrigued by phantom limb pain. With a phantom limb, pain is experienced as though the lost limb is still there, although the limb itself is no longer part of the body.<sup>20</sup> There is a disconnect between the visualised imagined body and self and the actual physical body. The authenticity of the self and its sensations are therefore undermined for sufferers raising the question – 'is the missing limb still part of the self?'<sup>21</sup>

Wright saw this as suggesting there was some kind of 'blue-print' in our brain for how our body ought to be (Wright in Roberts 2006 p 68). She became so interested in the questions it raised that when the Wellcome Trust advertised their first round of Sci-Art commissions she approached scientists to find a collaborator. I was curious about the way she describes the application process as giving her '*permission to make these approaches*' (Wright in Roberts 2006 p 68), and the way she framed the relationship she had with the scientists as *unequal*, perceiving the scientists as eminent with the authority and status of institutions behind them, in contrast to her own perceived position '*with no status*.' (ibid p 68) The institutional weight still maintains a discrepancy in power balance or levels of autonomy and ability to work in the way experience tells you will produce the more interesting images or work. I recognize aspects of this, however I feel more of an equal dialogue goes on between my clinical collaborator (as opposed to the institution) and myself while I am working on the **face2face** project. This may be the result of having built a relationship of mutual trust evolving over the duration of the project or maybe the generosity and unusual qualities of that particular clinician, Professor Joanna Zakrzeska. I wonder though if after the years of sophisticated and lasting collaborations with scientists Wright has had, whether she would perceive her relationship with her scientific collaborators differently now.

## Visibility

In considering the way images can play a role in pain encounters, Wright's images are significant and powerful. They not only raise awareness of phantom limb pain but raise questions around identity and its relationship to the visible. They are as much explorations of portraiture as they are explorations of pain. Along with a neurologist, Dr J Kew, and a neuropsychologist, Dr P Haligan, she was offered a Sci-art award to collaborate with people who had had limbs amputated. The resultant photographs depict how they experienced their missing limbs, in some ways working to legitimise or make concrete for others their relationship to them. See fig 48.

Using digital manipulation, the missing limb is made visible and tangible through photographic representation. As Wright is well aware, the images play with notions of truth and authenticity, giving weight to the individual's experience as opposed to what is visible to others. Wright asserts '*In parallel with scientific*

*extension of the boundaries of physical possibility, digital imaging technologies extend the possibilities of representation” (Wright 2012).*

The project resulted in 24 photographs displayed alongside short edited texts from interviews recorded with each of the eight people who participated (Wright: *After Image*, 1997). The photographs portray amputees in very ordinary or domestic environments, sometimes connecting the phantom to the body, at others leaving a space between the part where sensation is focused and the rest of the body. Wright also took a straight portrait of each participant in his or her own home as he or she wished to present him or herself without the phantom to ‘normalise’ what she felt might be viewed as more bizarre images of the phantoms. (Wright Roberts 2006 p 68). Wright says this was the first time she had worked with portraiture describing how she became interested in the relationship between the person and their surroundings - a feature which has continued into her ongoing research into identity.

Through photographic representation, this body of work (*After-Image*) gives visible form to parts of the body invisible to others but for the sufferer, still the locus of pain. The way the participants talk about their phantom limbs, witnessed in the fragments of text Wright appended to the images, makes clear how much for some the phantom remains a part of the individual’s sense of self, if they move the stump then the phantom moves, it is spoken about as though it as real as the solid body, for others it is more ambiguous and not necessarily experienced as part of the self. I find this fascinating.

*I can't imagine being without the phantom because it is there all the time and it is very much like eating or breathing: I ... would probably miss it if it went away'*

*'The real me is without the prosthesis; its uncomfortable; its not me. ... my self image is two armed.'* (GN text. Sourced <http://www.hodgkiss.co.za/NewFiles/twoicons/alexadetail.html> accessed 24.07.12).

*'The phantom doesn't respond to anything. Its just there. I can't scratch it, I can't hit it, I can't do anything with it; its not there except that it feels*

*as though it is there. I know it is mine because I can move it, but I don't really regard it as part of myself.'* (LN text, ibid).

It could be an example of Scarry's certainty for one person providing doubt for others but unlike for most chronic pain sufferers here there is something visible; it is the invisibility of the missing limb which ironically provides evidence and elicits belief in others. What is missing is what provides the proof; whereas with the pain sufferers I work with, it is what is visible, what is present and looks so normal, that elicits doubt from others.

Where my work intersects with that of Wright <sup>22</sup> is in giving visible form to invisible subjective pain experience. However, what is being made visible in Wright's work is the recognisable bodily form of the hand or arm that has been lost. What is being made visible in my work is the invisible and possibly less tangible emotions and sensations of a pain which cannot be pinned to any recognisable structural form or lesion. Rather than making pain literally visible, my work with chronic pain sufferers has to resort instead to metaphor, to making pain 'understandable'. It is meaning-making from a different puzzle.

## **PHOTOGRAPHIC PORTRAITURE WITHIN FINE ART**

### **Alexa Wright: problematising notions of identity**

Wright's stated starting point for her work is an exploration of 'identity'. In an interview with Keith Roberts during the *making faces* project in 2006, she describes sitting in her studio and wondering '*where do you start ?*' and concluding that '*you start with identity... That really is the core of everything*' (Wright in conversation with Keith Roberts, 18th July 2006 in Roberts 2006 p 68).

Along with many contemporary artists, Wright brings the social transaction within a portrait's production to the fore, particularly evident in her series '*I*' (1998-9). Here, through digital manipulation, she composites the disabled bodies of her

sitters with her own face, mapping her facial features onto theirs. She places the bodies of these disabled women in luxurious settings which give *'a grace and dignity to bodies which are culturally marginalised, seen as 'beyond the frame'* (Durden 2003 p 7). In doing this she is also opening up difficult questions about identity construction and perception, specific to the processes of photographic portraiture. Her photographs acknowledge portraiture as the construction of one identity by an 'other'. Like Dryden Goodwin's (discussed on page 168), Wright's work hovers on a fragile line between what is ethically acceptable and unacceptable, and it is this tension, the dangerous nature of this liminal space, which gives the work much of its power.

In one of the images within *'I'* we see a tall elegant woman in a long red dress, made of material of a silky appearance, suggesting movement and opulence – neither associated with traditional images of disability - her left arm is missing with no prosthetic replacing it (see fig 49a). The environment she is standing in is one of grandeur, suggestive of a stately home. In front of the figure and to the right as we view the image, we see the right hand side of an ancient marble sculpture of a naked female figure on a pedestal. Behind the sculpture and between the sculpture and the figure is the reflection of the back of the sculpted figure, the right arm clearly visible, as though if the shadow moved to the left it would slot into place and provide the girl's missing arm, but the left - possibly missing - is out of frame. Looking more closely at the figure in the photograph it becomes apparent that the face of the girl is that of Alexa. It raises questions about how we view disability, how in Dwoskin's words we search for uniformity and harmony in the body (Dwoskin personal communication 2001a). We have no difficulty with perceiving sculptures from antiquity as beautiful with or without missing limbs, but society has much more difficulty perceiving living figures with missing limbs as beautiful.

Is Wright consciously referencing Marina Warner's discussion of classical sculptures, changing notions of the female 'nature' and body and its plural significations? Warner's evocative description of Nike the Goddess of Victory in *Monuments and Maidens: The Allegory of the Female Form* (1996) is brought to mind. Although the head and arms of this sculpture are missing Warner describes the skill with which the sculptor *'has carved her legs, her torso and her wings out of the soft-apricot-coloured stone'* which *'fills the space around her with the energy of her flight that the ecstatic thrust of her other limbs and the*

*probable set of her head are unmistakably implied, although their exact position cannot in fact be ascertained'* (Warner 1996). A power is ascribed to the form through the existing limbs with which the viewer has imbued the rest. The winged statue of victory has been used by so many nations and in so many (some repugnant) ways, it reaffirms that we construct an identity around it, which we want to construct, we fill in for the missing limbs in the way our historical context and culture encourages us to. Do we not do the same with disability and illness? Do we not fill in the missing spaces for ourselves, bringing our identities, our needs and not the subject's to bear upon them? We re-constitute their narrative and their identity in line with our own and not the subject's worlds.

According to neuropsychologist Paul Broks: *'There isn't a single answer to that question, "who am I?" – it will depend on who's asking the question. It will depend on the circumstances, and on who wants to know what about me'* (Broks 2009 p 80). There are no definitive answers to questions of identity and perhaps no definitive self. Is this the conclusion Wright's work is leaning towards?

In another image (see fig 49b), a much smaller figure is seated on a very low chair, the figure's proportions are clearly different from the norm, much smaller than the previous girl. The environment again is sumptuous, there is a marble bust on the left hand side on what appears to be a tall pedestal, there is a painting of a reclining woman in a gilt edged frame on the wall behind and a wooden chest with ornate carvings. Once again on close inspection the face of the figure is that of Alexa. The format continues throughout the series, with the sometimes clothed, sometimes naked, bodies of disabled women, situated within elegant surroundings and with the artist's own face superimposed onto theirs. What is Alexa aiming to do with this series?

When I showed the images to the pain sufferers during one of the **face2face** workshops at the National Portrait Gallery, they objected to them, feeling that Wright had taken ownership of other people's identities. Although I understand this response, what I feel she is doing is raising uncomfortable questions - the most obvious of which is *'where does identity lie?'* If identity lies in the face, then all of these photographs are actually portraits of Alexa - but they are not. We have to look elsewhere to discover identity, and perhaps all the trappings of identity, such as environment, clothing, facial features, chosen objects such as

early sitters used to represent their identity or status, are all distractions. We have to look beyond these surfaces and examine the process of looking, the process of exchange, the process of perception and association, in other words she is encouraging us to examine how we construct and perceive identity and acknowledge the possibility of multiple identities.

Broks refers to ways in which we know we are embodied, in that we have bodies which affect our sense of identity, we have a sense of agency and a sense of control over that body; we like to think of ourselves as '*unified and singular*', that there is only one of us and that we have a continuous identity (Broks 2009 p 81). However he raises the possibility of distinctions within the self; a *minimal* or core self, the self at the present moment which requires embodiment, and what he calls the *extended* or autobiographical self from which we get notions of continuity. He proposes that the self could therefore be described as a continuous being with a history, an autobiography, a sense of the future and a capacity to anticipate what's likely to happen to us or we hope or dread will happen to us, concluding that partitioning the self up in these ways (minimal and extended) opens the possibility for developing scientific theories of selfhood. Broks claims that clinical observations suggest that the *minimal* and *extended* selves have different neurological underpinnings (Broks 2009 p 81). Does this imply our sense of our own identity is constructed through different processes working together or alongside each other? Is it possible for one type of self to remain intact while another is ruptured? What happens when one of these partitions gets disrupted, when the self is not experienced as continuous, where the embodied present does not fit easily into the narrative we or others have constructed for us, what then happens to identity? What Wright's photographs do for me is to reinforce the fallacy of the notion that identity lies in the face, that the face or the eyes are somehow a '*window to the soul*'.<sup>24</sup> Wright's work also raises questions about how we view disability in addition to how we view the portrait, forcing us to ask whose portrait is being constructed, the artist or the sitter's – or even the viewer's? Broks, when asked about identity and construction of the self in an interview for the Wellcome Trust's exhibition on identity, observed that:

*We have, in neuropsychology, lots of pretty good operational definitions of things like memory, language, action, agency, and things like that. But what we don't really have is a really good theory of how it all comes*

*together to produce the person, or the sense of self. ... It's still a very new question for neuropsychology and for neuroscience generally. So it's a bit like the question of consciousness: we all know what it is and we all think we understand it at one level, but actually, when you come to define it, it can be very, very difficult. It eludes precise definition. (Broks in Arnold et al. (eds) 2009 p 80).*

Wright continues to explore issues relating to the construction of identity and the toleration of unstable unfixed identities. In collaboration with Professor Alf Linney at University College London she developed *Alter Ego*, 2005, and *Conversation Piece*, 2009. *Alter Ego* is a screen based installation where visitors interact with what appears to be their own mirror image but is in fact an avatar onto which an image of the face is mapped in real time. In Wright's words *Alter Ego*, 'invites people to question the various facets of their own identity'. (Wright: alexawright.com accessed 22<sup>nd</sup> august 2012). What I find particularly interesting in *Alter Ego* is the fact that the mirror image not only appears to reflect expressions but to react to them, initiating a dialogue with the self, but also unpicking the processes of exchange via the face. In *Conversation Piece*, 2009, the examination of social exchange is explored further, investigating, 'the extent to which any human interaction is concerned with projection and imagination.' (Wright 2012).

The relevance of this work to the pain sufferers participating in **face2face** project is perhaps in the revealing, the making visible, of the processes of projection and reception during dialogue and ways in which these are affected by the other, - capable of resulting in a skewing of relationships. The disconnect between what is visible via the face and what is behind the face becomes more extreme when that face is in pain. It is with this intersection of projection, reception and processing that my own work in **face2face** is also concerned. When a face is frozen by pain, it allows others to project onto it. The other reacts to the perceived expression and then the pain sufferer reacts to the other's response, resulting in a destructive cycle of miscommunication.



## Dryden Goodwin

The work of artist Dryden Goodwin brings this process of projection directly onto the photographic surface. In fact in *Cradle*, 2002, it is literally etched or scratched into its surface, becoming a meeting point for artist and subject's identities and subjectivities (See fig 50). Through drawing, photography and film Goodwin treads liminal lines between subjectivity and inter-subjectivity. What I have found fascinating is the different approaches he takes to portraiture and the representation of the experience of others, and variety of ways he has navigated consequent difficult ethical issues inherent in making representations of another.

For example in *Cradle*, 2002, and *Capture*, 2001, series' of photographs of passers by in streets and buses (See fig 51), the artist appears to superimpose his internal subjectivity onto the external appearances of his subjects. The work is powerful because of the ambiguity of the morality of this and questions it raises about both portraiture and photography. The photographs do not appear studied, or consensual, but as fleeting moments caught while someone is unaware, travelling on a bus or walking in the street. It is Goodwin who captures this moment, this identity, not only through the lens and the click of the camera but within his web of drawn lines etched onto the surface; a net of neurons, - an etched cradle which modifies the subjects identity via the artist's will. Goodwin's marks emphasise a sense of embodiment and the corporeality of identity, but by scratching onto a moment from someone else's past with his own hand in the present, he is to some extent disrupting their continuity of identity, time and self, he is disrupting what Broks (referenced earlier) would call their '*autobiographical selves*'.

Identity and its fragility are something which those with facial pain are particularly conscious of, and particularly keen to retain as much control over as possible. For them, both Wright's and Goodwin's work (discussed in the **face2face** workshops) appeared to pose a level of threat. It is however at this level of threat that both pieces could be said to *work* as 'art'. Goodwin himself said he thought it was through the tension between the ethical and less ethical that his work lives and has its effect (Goodwin 2011).

In his recent project, *Linear* 2010, a collaboration with London Underground and staff on the Jubilee line,<sup>25</sup> Goodwin found a different resolution to the ethical issues of constructing another's identity through the lens. Here the subject's voice is clearly heard, (quite literally), and as it is central to the work, allows authorship of the portrait to shift towards a more shared position – while the artist maintains final authorial control through the video editing process. *Linear* is 60 short two-minute films in which Goodwin's hand is seen drawing a pencil portrait on a sheet of paper of different members of staff who work on the Jubilee Underground Line. The sound track is an edited two-minute interview of the subject talking about their work. The ethnic and age range is vast, offering tiny spotlights on humanity. Necessarily this must have meant selecting one aspect of a person's character or experience over another and in this way the artist as editor, is editing their identities. I am inspired by this work which includes the subject within the process, and allows the voices of others to extend what one single artist might achieve, while maintaining sufficient distance from the subject along with a highly skilled aesthetic, to allow the work to situate itself within a fine art context.

Scratching onto a photographic portrait in this way has parallels with Elizabeth Grosz's vision of the body with its own narrative inscribed within it. Her redefinition of subjectivity (Grosz 1994 p vii), incorporating a corporeality, has overtones with the photographic 'skin' being scratched in to to plumb its depths:

*The wager is that all the effects of subjectivity, all the significant facets and complexities of subjects, can be as adequately explained using the subject's corporeality as a framework as it would be using consciousness or the unconscious. All the effects of depth and interiority can be explained in terms of the inscriptions and transformations of the subject's corporeal surface.* (Grosz 1994 p vii).

The body is theorized within Grosz's work as part of the construct of subjectivity rather than something affected by subjectivity (Grosz 1994 and 1995). This reframing of subjectivity could be employed as a starting point from which to explore physical objects/images as flexible spaces between and impacting on subjectivities uniting body and psyche within notions of both identity and pain

experience. It moves us away not only from dualistic perceptions of mind and body, but also the roles of clinician and patient.

Grosz's theory has relevance not only to the lived experience of pain and current theories of pain mechanisms within medicine, but to photographic practice and notions of representations of the 'sick' other. Goodwin's practice of intervening within the image heightens the sense of embodiment of identity within his portraits and reminds us of the physicality of the construction of the self and the materiality of the photograph which stands in for it.

Participants in the **face2face** project frequently reported that they had been changed by 'pain', that their lives and identities have become fragmented - their narratives, often chaotic, support this. If this sense of fragmentation, loss of the old and re-making of the new self is understood through purely psychological analysis then the body is marginalised. It is within the body that pain is re-making people and affecting the constructs of their subjectivity and intersubjectivity. Note the title of Elaine Scarry's seminal book on pain, *'the making and the re-making of the world'*. Both Scarry (1985) and Biro (2010) more recently premise their work on the incommunicability of pain and the effect this has on the person who has pain. In **face2face** the space between selves/perspectives is visualized less as empty space and more as animated material with an agency of its own impacting and touching on boundaries of body and psyche as one material. The '*space between*' becomes charged and the photographs appear to have a direct effect upon transforming it into a negotiated space.

## **Helen Sear**

Helen Sear also investigates photographic portraiture and ways of indexing identity within the portrait via other means than a faithful reproduction of the face or attempt at 'likeness'. In fact it is evident in the series' *Inside the View*, 2004-08, *Beyond the View*, 2009 and *Sightlines*, 2010, that the face is specifically avoided as an index of identity, it is intentionally hidden from view. Elements exterior to the self, such as the figures of ceramic birds, or landscape and environment, are used to provide insights into the inner worlds of her subjects. See figs 52, 53, 54 and 55.

In *Sightlines*, identity is constructed by the viewer somewhere at the intersect between the faces and attitudes of the birds and the bodies of the sitters. Placing the construction of identity in the hands or rather 'eyes' of the viewer emphasizes the projection and interpretation of others as a key part of identity creation. It suggests that identity is not solely constructed by the individual but by those they come into contact with. In her accompanying essay to Sear's work in *Inside the View* (2012) writer and academic, Sharon Morris, identifies the ceramic birds as operating as masks - concealing the faces of the women yet also performing acts of communication:

*The bird artefact operates as a mask, instigating the performance of that game of hide-and-seek fundamental to the creation of the sign conceived as the loss of the thing. But the sign conceived as mediator between I and you is dependent upon a dynamic third term, the it: and here in place of the it we find the ceramic bird. (Morris 2012 p 58).*

It is paradoxically this function of the mask that it reveals rather than conceals identity. When I used to work with sick children at Chelsea & Westminster Hospital we used masks within many of the drama sessions. What became evident was that what might be seen as more essential or truthful aspects of the children's personas emerged more strongly when they were wearing masks, than when they weren't. Hiding the face allowed identity to emerge through the tiniest of movements or responses, through sound, gesture and interaction. It almost suggested that the naked face itself acts as a mask and the mask conversely exposes the person. In this way, perhaps those with facial pain have a more honest relationship with their face, in that they do not experience their own faces as indicators or accurate expressors of emotions and/or identity. (Although many of those taking part in the NPG workshops seem to retain vestiges of a belief in the face as an index of identity in relation to others).

One thing Sear's portraits highlight for me is the instability of identity, its chameleon and ever-changing nature. Sear's photographs present identities as in a state of flux rather than as fixed entities. Equally, they suggest its relational nature; that it comes into being at points of intersect, for example: between the environments and the subjects; between objects - in this case ceramic birds and

the figures, perhaps between the psyche and the body, the past and the present, between the artist and sitter, and between the artwork and the viewer. Can a comparison be made with the narrative that comes into being in the medical consulting room, at the intersect of clinician and patient subjectivities?

*Beyond the View*, 2009 is a poignant and powerful series of portraits (See fig 54). Endowed with a seductive aesthetic, the viewer is drawn into the relationship between the ethereal silhouettes of the back of women's head and shoulders, and the disrupted landscapes peppered with fragile flowers, abstracted and dissolved by being seen through what appears to be a gauze or net. In some, the flowers predominate, in others the landscape, but always the figure appears as a ghost or shadow. From my memory, what punctured this and placed the photographs in a liminal space between attraction and repulsion giving the work its power, when I saw it at Hooper's Gallery in Clerkenwell, was the information in the accompanying texts that these women were immigrant prostitutes, and this was the landscape seen from the roadside where they worked. The identity of the women are hidden from us as they are from the men who exploit them, but fragments of identity are suggested through the choice of flowers, the dream of the landscape, and the duality of the flower as a symbol of femininity and/or sexuality. There is a tension between surface and depth, between sensation and dream, past and present. Of her practice Sear wrote:

*'Using the camera ... I have attempted to recuperate the body into the act of looking and explore the corporeality of vision through the various processes of layering, drawing, excavating and rupturing, both in the still and the moving image.'* (Sear 2010 cited in Chandler in Sear 2012 p 126).

The viewer is disorientated within the planes of the photograph. Once again, identity is not fixed within facial features but located in an interplay between the self and its shadow, or in Sharon Morris' words the self and the collective, *'the paradoxes of unity and multiplicity ... raising a politics of identity, the common field as one collective'* (Morris 2012 p 86). This view is slightly reminiscent of that held by Orlan, that an individual face tells us truths not necessarily about itself but about the multitude or collective *'in other words, the civilization of which they are a part. Individual faces are sponges which soak up a culture in a figurative sense'* (Ewing 2006 p109).

I am reminded of subject W5 in the **face2face** project, who described herself as a ‘*shadow sandwich*’, and who brought in a loaf of decomposing bread, instead of a burgeoning landscape through which to index her identity. Something of the impression is the same in that in neither Sear’s portraits nor those co-created with W5, are the features visible; the self is evoked through the qualities of the environment the silhouette is embedded in and exists not only as a shadow within the image in the present, but also as a shadow in relation to its past.

*‘In Sear’s art the crossing of the threshold represented by vision has been an abiding preoccupation, one that, fundamentally, has drawn her to photography, and to film ... If eye and aperture forms recur in Sear’s imagery, they are opaque, often appearing as reflecting mirrors or pools of blinding light rather than windows or channels of connection. For Sear photographic vision is occluded; it is not just a layered process (the revealing of which in her work has in itself led to forms of opacity), but it is also a site of enquiry, a subject, one to be unraveled and examined as part of the work’s conception and making, from idea, from theory, and from intuition into practice.’* (Chandler 2012 pp 124- 125).

In the series *Twice ... Once*, 1998-2000, the eye is also disorientated, the position of the photographer or the subject is unclear. Sear superimposes two negatives of the same subject onto each other, obscuring a unified index of identity, and suggesting, in its place, an identity which is multifaceted and multilayered. The process blurs the facial features; they become almost unrecognizable and indistinct, reminiscent of Boltanski’s enlarged photocopies and newsprints. Do these early portraits of Sear’s hint at a relationship between individual and collective identity developed further in her later work? Is my aim of reporting the clinical findings of the **face2face** project in the future through composite portraits of clinicians and patients influenced by both Sear and Boltanski? Is identity always a mix of projection, reflection and embodiment? Do we all construct our identities in relation to others, or is there, in Brok’s words, some ‘core’ identity within each of us? If so, how and why do we want to, represent this photographically?

## Deborah Padfield

### Portraits of pain

My approach to portraiture has always been one of co-creation, a meeting of subjectivities: it forms the basis of my fine art practice within most of the **face2face** project.

Perhaps because I am working within healthcare, my resolution of the ethical and aesthetic tensions between where I hope the images go and where participants need them to go, between my expectations and hopes for the work as an artist and my medical collaborators' expectations and needs for it, are necessarily negotiated differently from fine artists working outside the health sector. However, in a similar way to Goodwin's observations about the tension in his work being between the ethical and non ethical, acceptable and non acceptable, I feel the potency of my own work, if it has any, is situated in a liminal space – albeit a different one to Goodwin's. It is these liminal tensions which perhaps give it validity, (as well as its guiding ideal to promote healing) and it is predominantly liminal spaces with which it is concerned: for example; the physical, metaphoric and linguistic spaces between patient and clinician, aesthetic spaces between artist and participant, the intentional and linguistic spaces between: artist and medical professionals; researchers and institutions, 'health and safety' and healthy expression, between the architectural clinical environments pain encounters take place in and the individual bodies and psyches through which they are processed, between language and image, perception and physiology, what is spoken and what is communicated, and what is felt one side of a painful face and what is perceived on the other. It is these liminal spaces and how we might navigate them that the project sets out to explore, to understand and use this understanding to promote healing.

### Co-creative photographic process

The bulk of the creative practice of the **face2face** project involved co-creating portraits or images of their pain with five pain patients from UCLH with different types of facial pain. During *perceptions of pain* I had developed a process of co-creating images with pain patients, which aimed to give visual form to each

person's unique experience of pain. Combining the creativity and strengths of pain sufferer and artist I believe enables us to arrive together at a stronger series of images than either I or they would have arrived at alone, which can resonate with people outside the process. Patients who co-create images directly control how their pain is visualised and represented to others, rather than being placed on the receiving end of the medical gaze.

I continued to develop and refine this process with facial pain sufferers during the **face2face** project, becoming increasingly interested in the relation of narrative to their experience and to their changing **perceptions of pain** as the sessions went on and as they progressed through their medical treatments/management. It was an intensive process, working with participants ideally (but this did not always transpire exactly) at three points in their pain management journey. The process lasted for between six months and a year with each participant and involved between nine and twelve one to one sessions. In the sessions we discussed their experience of pain, how they might visualise it, any metaphors they already had for it, if pain might be reflected through any particular materials, colours, light or absence of, or significant objects they brought in. In subsequent sessions we would review the images from last time, selecting and modifying those that were closest to their experience, and either re-take them, refine them or take new photographs using objects they or I had brought. Usually, the sessions took place in a room we booked in the hospital, but sometimes they took place in the Slade photographic studio or around a location which related to aspects of their pain experience or their ways out of pain, for example walking round Hackney looking for derelict buildings or in a participants' garden in West Hampstead. See figs 56 and 57. Each of these sessions was recorded and although there isn't space within the scope of this thesis, an analysis of these exchanges would be a fascinating piece of research for the future. They bring clearly into focus the role I played as an active participant in the construction and reflection of narrative, but more than that they bring out the unavoidable relationship between personal narrative and pain experience.

Although we used predominantly objects as metaphors for their pain, I still see the photographs produced as portraits of pain; in some cases, they did also include representations of the face or body in a more recognisable form or representations of the face/body within metaphoric environments. The images



reinforce Elkin's view that *'every picture is a picture of the body'* (Elkins 1991, p1), though in this context it could be extended to *'every picture is a picture of the self'*. The process was negotiated differently with each person who participated and I am sure there are times where I have been more successful and times where I have been less so in re-presenting their experience 'accurately'. In some ways the portraits produced are a fusion of our objectivities as much as our subjectivities - the distance the photograph provides has been used to 'observe', 'witness' and 'unpick' some of that pain experience, rather than present it as fixed and stable. Carlin and Cole support this argument: *'Padfield makes the case for objectifying pain by means of artistic representation so that sufferers can disassociate the pain from their being.'* (Carline & Cole, 2011 p 105). Photographic portraits and the identities constructed within them are able to remain 'unstable' eliciting different narratives and allowing for the possibility of uncertainty and the not yet known, an essential part of being human.

This elasticity of identity is further extended through the lengthy process of creating multiple portraits over time. The aim of working with people at different points in their pain journey, before, during and after treatment, was to get away from fixing identity and perception within a 'pain identity' and to allow multiple and changing **perceptions of pain** and identity to emerge. The aim was not that I as photographer was in control of a gaze which shed light on and fixed experience or identity for others to see, but that together we revealed aspects of experience, perhaps neither of us knew were there. Led by the subject the camera allowed significant moments of narrative to be viewed and focused on. Kozloff, speaking of Nan Goldin's work, speaks of a fluidity of 'raw contact' (Kosloff in Ewing 2008 pp 76-78) between photographer and subject. The co-creation process at best is an example of 'raw exchange', aimed at capturing through the medium of photography that which is not normally seen, that which is within the power of the subject to choose to reveal or conceal. Jane Fletcher in *'Sweet Liberties: Narrative of resistance and desire'* (2003) describes the photographic encounter as:

*two or more people in some sort of dialogue – be it a collaboration or a battle of wills. Two or more people co-operating with, or resisting, one another. Two or more people acting upon different agendas and*

unarticulated desires. *Two or more people absorbed in each other or turned in on themselves* (ibid p 51).

It is in a spirit of dialogue that these portraits were made, and in a spirit of dialogue that they are offered to the medical profession to use within their clinical encounters if they wish.

### **Photographing pain**

There have not been many images of the internal subjective experience of pain, or of chronic pain in Western Art. Art Historian, Scott Karakas,<sup>27</sup> questions why although '*Chronic Pain is a powerful human feeling, ... relatively few depictions of the condition appear in the history of the visual arts.*' (Karakas 2011 p 87). He offers shorter life spans historically as a partial explanation for this as well as the possibility that chronic pain is internal and therefore invisible to others (Karakas 2011 p 87/88 in Giordano 2011).

Suffering, on the other hand, is almost ubiquitously depicted in Western Art, which is why I have chosen not to focus on it in this thesis; it is implied to some extent in the work of most artists and would therefore become a never ending thesis. The most famous visual icon of pain is of Laocoon and his sons<sup>28</sup> (see Fig 15); there are also countless images of the sufferings of Christ and of the saints, and the suffering and pain of punishment of criminals became almost a genre in the Middle Ages and the Renaissance (Brody 1987). However, all of these visualisations depict pain through attacks on the outside of the body; in the former the attack by sea serpents and in the latter attacks by devils and monsters. There are some more recent depictions of pain which do suggest the ravages of physical or chronic pain, such as in the work of Frida Kahlo, Edvard Munch, and Vincent Van Gogh, but in pointing out the distinction between other visualisations of pain and mine, academics Carlin and Cole observe:

*The point here is that all these images represent pain and suffering in a particular person's body. The fresh and unprecedented move made by Deborah Padfield is to create images of pain itself, outside of the body, for therapeutic purposes within the health care setting* (Carlin & Cole 2011 p 106).

They cite Gillray's well known image of gout (fig 18) where demons inflict pain on the body so we have:

*'in other words, a body in pain – not pain itself ... Padfield's photographs mark a radical disjuncture in the history of representations of pain. As far as we know, in Western art all prior paintings, prints, woodcuts, drawings, lithographs, posters, photographs, sculptures, and so forth, have represented pain within a particular human or animal body or bodies.'* (Carlin & Cole pp 106-107).

### **Photographs of pain as triggers to dialogue: PAIN CARDS**

One of the uses to which I wanted to put a selection of these images of pain, was to develop a pack of pain cards (a series of images of pain printed as playing cards, see figs 58 and 59) which could be used in pain clinics with patients who had *not* been involved in creating them. For the images to be useful to people outside the making process they had, by necessity, to be images of characters and intensities of pain itself rather than of pain happening to a particular person or a particular part of the body. They also had to be ambiguous enough for new patients to be able to project their own experience onto them, rather than reflecting meaning which was pinned down within a particular individual's narrative.

I had developed literally hundreds of images with pain patients which had to be selected down to form a manageable number of images in a pack for patients to be able to look through prior to their appointment. The image selection process highlighted once more possible tensions between aesthetic and medical requirements. A compromise was arrived at where I made an initial selection of what I felt were the strongest images for each type of pain or from each series, using my own subjective judgements and knowledge of which images people with pain had responded to along with the images most frequently selected in the pilot *perceptions of pain* study, and then I took this long list to my clinical collaborator and one of her colleagues to help form a short list, using their knowledge of patients' experiences and the needs of their patients. Once again, negotiation was at the heart of the process. We ended up with a pack of 54

images of different qualities and characteristics of pain printed on enlarged 6" x 4" playing cards (see fig 58). The number 54 appealed to me as I thought it was the number of cards in a pack of playing cards. (I since discovered it is 52 and two jokers.) There was also an oblique reference to chance, the chance that leads one person to develop chronic pain and another not, which was perhaps subterraneously running through my mind (also perhaps a reference to Borland's *Home Testing* installation, 2005 at Truro); alternatively the possibility that you could hold of some of these cards in your hand and select them ie that some aspects of what could be framed as chance could also be within one's control?

### **Vanitas Cards**

In Carlin & Cole's analysis of ***Perceptions of Pain*** interestingly they chose to relate the images to Vanitas Cards:

*The photographs she produces [Padfield] in consultation with chronic pain patients are striking, and her efforts represent a new moment in the history of the visual representation of pain (though we suggest that her images recall the theme of vanitas in art history) and also a new moment in patient care. (Carlin & Cole p 105).*

Vanitas is an interesting concept in relation to these images. Photography necessarily recalls something which has been lost (see Barthes 1993); a frequently discussed aspect of chronic pain is also a sense of loss, not only of the healthy or pain free body but of something deeper, way back within an individual's history; the loss perhaps of something that never was. In ***perceptions of pain*** I had photographed ice melting, not only in response to literal descriptions of pain's temperature as either ice like, or fire-like or occasionally both, but as a response to my own experience of living with pain. The change from solid to fluid form which found new shapes as it melted seemed to parallel the process of pain, where what was solid and known changed to something less concrete and new. It reminded me, that as with the life cycle, something has to be lost, in order for something else to come into being; that change can be seen as evolution rather than loss. I wrote something similar to this in ***Perceptions of Pain***:

*The photographs were made by the sea as they melted in the sun and dissolved back into water. For me they are an attempt to experience loss of what is 'known' not as absence but as a chance for change and transformation – an acceptance of the state of 'unknowing' and 'impermanence' as part of a continuum we are all part of. (Padfield 2003 page 37).*

I think it is only now that I realise how central to pain and suffering, the notion of loss is. Perhaps Carlin and Cole had hit on an essential element to these images before I had fully begun to be aware of the relevance. Images in **face2face** literally depict loss, as with fig 83, whose newspaper letters mark out its importance starkly on a black background. In other images loss is referenced through the shadow, or the changes in decomposing foods and deteriorating buildings which suggest a loss of identity and health, a loss of function. It adds another argument for photography being the most apposite medium with which to carry out this project and reflect pain experience.

## **Film**

### **Moving into film: a natural progression**

Where I felt I had fewer ethical obligations to involve my subjects in the creative process was in editing the film I made as a response to working in a medical pain environment. I had begun to become interested in the exchanges taking place in the spaces between people and photography's effect on that space, more than in the individual photographs we produced. In several previous projects I had interviewed people talking about objects or places which were meaningful to them, or about their pain experiences, or experiences of ageing, etc, while photographing them. This was partly to elicit relevant narrative, but mostly to engage them in conversation which might produce more animated and natural expressions. Initially I had placed excerpts from transcripts of the interviews alongside the photographs, but later I began to integrate the texts within the images more fully by creating digital sequences of still images with fragments of text running across them.

The first person I experimented with using this process was a beautiful Portuguese woman who had dementia and who was losing much of her English due to her condition, reverting back to her mother tongue. She moved between both languages, with Portuguese becoming more dominant as she became more emotional. I became very aware of the responsibility of selecting which fragments of text were attached to which image, as the nature of the text completely changed the reading of the facial expression and thus in some ways was a form of identity construction which she was not complicit in, although she had given permission for each individual image to be used. The piece was called *Helen's Song*, 2008 and shown at the SW1 Gallery, Westminster.

Film seemed a natural progression of this desire to find a way to reflect narrative verbally as well as visually and to set up relationships and tensions between the two - fragmenting as well as constructing dialogue. It seemed the perfect medium for creating unusual juxtapositions, in keeping with the surreal nature of the pain experience itself. It was also a way of extending reflections of identity over time. It was the first opportunity I had had to experiment with time based media, and it allowed all sorts of possibilities which still photography did not, at the same time as presenting me with enormous technical challenges.<sup>29</sup>

### ***duet for pain (2012) developing out of facing pain (2011)***

In this work I wanted to present the bizarre and alienating world of the medical environment as a background within which highly personal exchanges and experiences take place. I also wanted to explore the construction of patient and clinician roles, the meeting points of different perspectives which intersect and disconnect within clinical pain dialogue, but while doing so frame the processes of photographic portraiture and filmed interviews as equally constructions of role and identity. See figs 60 and 61a.

I conducted filmed interviews with consenting patients and clinicians about their experience of having or of treating facial pain. The same process of photographing and re-photographing that I had used in the still photographs, found its way into the filming process, with the interviews being filmed, projected and then these projections re-filmed. The aim was to embody within the piece aspects of projection and reflection which take place during the process of

communication and dialogue. The two interviews I finally selected to construct the dialogue were both projected onto imaging devices and re-filmed; the patient, (who had been a former model and whose identity had literally been constructed through the lens), was filmed projected onto a shallow pool of liquid within a photographic tray housed within the frame of a metal trolley with sterile/clinical associations; and the clinician, (also my main collaborator in the project), was filmed projected into a light box used for studying x-rays within her consulting room, so that her disembodied face appeared as though from within an imaging mechanism, looking straight back at an empty dental chair. Both participants were incredibly generous with their time and ideas but also with the freedom they gave me in the editing process. Both were offered an opportunity to see the final piece before it was shown publicly and neither took this up. The courage in this decision was immense, probably more so than they realised at the time. It made me horribly aware of the responsibility of the editing process, through which identity is literally being sliced and re-assembled, alongside an equal feeling of relief that here I could allow imagination to roam unhindered by a need to reflect any individual's identity authentically. This film was attempting to reflect the nature of pain dialogue and the relationship between the face, narrative and identity; it was not attempting to create faithful portraits of particular individuals - albeit I had extraordinary individuals as my subjects.

There are precedents for using the experiences and perspectives of others in contemporary video work, and precedents for crossing the boundaries of fine art and medical research and education as with Christine Borland's work. I have always admired the work of Christine Borland because of its dual function investigating areas of science while keeping the power of its aesthetic central to the way it communicates. Borland '*makes art which deals with the body, and with our emotional, imaginative, medical and institutional sense of self*' (Bradley 2006).

The aesthetics and the ambiguity in Borland's work, *Supported*, 1990, *Shot Glass*, 1991, *The Dead Teach the Living*, 1997, *The Velocity of Drop*, 2003, and *Preserves*, 2006, allows it to communicate in a way which research papers however good would find difficult to parallel. There is something which the visual material adds which cannot be literally translated into prose. Her work offers an open, often ambiguous, space allowing the work to problematise the body, its relationship to self, to other, the institutional, history and memory.

*Simbodies and Nobodies*,<sup>30</sup> a film resulting from her observations of clinical training at Peninsula Medical School, is highly charged, ambiguous, and questioning - both extraordinarily difficult and yet extraordinarily beautiful to look at. Engulfed in darkness, flitting between high definition images alternatively reminiscent of birth and death accompanied by the sounds of a breathing machine, the film captures a liminal space between being and non-being, reality and representation. It is not a space which can be captured by words alone, it relies on its visual structure and aesthetic for its meaning.

This dependence on qualities within the visual material as much as on what is said or happening within it, is what I aspire to. I wanted my work to somehow strike an even balance between respecting the experiences and ideas of others as they wished to be represented but feeling free enough to use these experiences to support my own aesthetic and conceptual purposes.

### **Film as an immersive space with the potential to disorientate**

The idea for the film was to immerse the audience in some of the contradictions as well as the poignancy and irresolutions of pain dialogue, and for that to work, I had to be free to move between perspectives and create a visual rather than a logical environment. I aimed to affect sensation as well as emotion and to disorientate the audience rather than providing any answers. As Berger (1972, 1980, 1982) affirms there is a value in the dream space which images and particularly film can conjure up, revealing through experiential rather than logical means, what is less conscious, less known, less tangible.

As a response to this desire to immerse the audience in the physical as well as metaphoric space of the dialogue, the first film ***facing pain***, 2011 was shown at the Menier Gallery, London originally projected onto two screens opposite each other with the audience positioned on cushioned stools between them. (See Fig 61b). The clinician was on one screen and the patient on the other, with the sound alternating between them although both were always visible. This meant the clinician's film was seen first with sound, while the patient was silent and then on the other screen the patient was heard while the clinician was silent. It was pointed out to me that this could give the impression that the clinician was silencing the patient, or vice versa, which contradicted the aims of the film. It



also occurred to me, while editing, that there were many visual as well as verbal references to the other film within both pieces and that they might work better integrated into a single split screen film. Consequently I revised the film for single screen, now called ***duet for pain***<sup>31</sup> so that it reads more as a dialogue and I believe more successfully reflects the disjuncts as well as the connections between different perspectives on the face, identity, pain and its management.

In a review for the *bmj Medical Humanities* ethicist, Dr. Ayesha Ahmad wrote:

*Pain is either my pain or your pain; the meeting-point for this is the 'membrane', which featured as a centrifugal point for this exhibition. In this juxtaposition, I am reminded of Maurice Merleau-Ponty's work on the 'Invisible and Visible Body', whereby he said that the 'invisible' etches and scribes onto the 'visible', neither of which would exist without the other. It is through communication that the intersubjectivity of the invisible, the pre-given body, is transcended. Such communication in Deborah Padfield's work was enabled through a conversation with each participant and resulted in each photo generating its own energy. (Ahmad 2011).*<sup>32</sup>

Although here she was speaking primarily of the photographs, she spoke of a space which inter-wove subjectivities, allowing those of the audience to intersect with those of the clinical and patient participants, the sort of space I wanted to create with the film. It is with communication and the meeting places of subjectivities that the films and the project have become concerned and it was as a membrane between subjectivities that I wanted the film projections to be experienced.

Denna Jones, in a review for the *Lancet*, called the film the '*sleeper hit of the exhibition*':

*Alone on screen with her silent, unseen interlocutor, former model Francine Ozarovsky is petite and bird-like with a whispering, mesmerising presence. Her 7 minutes alternate with a second screen where Zakrzewska discusses pain as symptomatic of both psychological and physical issues. The skill clinicians need, Zakrzewska says, is "empathy". Deft employment of empathy allows the patient to give the clinician the diagnosis. Whether she realises it or not, Zakrzewska*

*comes across as the doctor we all wish we had. Padfield's film is a powerful clinician–patient dialogue and it is a remarkable first stage from which all the co-creators can move forward to making chronic pain less of a lonely, personal journey.* (Jones, 30<sup>th</sup> July 2011, see appendices p Lxxxvi for full text).

Although the film itself was less of a co-creation, and more an authored piece of work, the project, associated discussions, symposia and exhibition taken together form an integrated collaborative piece of work. If together we have begun a process which can shed light on pain experience and dialogue and help make it less of a '*lonely personal journey*', then that is something of which all of us, myself, the clinical team and particularly those with pain who worked with us, can be proud. For me these types of reviews validate the use of the experiences and expertise of others within fine art practice, and strengthen the argument for extending its boundaries to accommodate them.

# MEMBRANE

*Thus silence will no longer be that which has not yet come to language, that which is still lacking words or a sort of ineffability that does not merit interest from language. Silence is the speaking of the threshold. (Irigaray 2008, p 5).*

This chapter is an attempt to understand not the silence of the threshold but ‘*the speaking of the threshold*’. It analyses selected fragments from all of the strands of the **face2face** project. Occasionally, where relevant to the argument, it draws on other public projects I have undertaken while working on this thesis. It focuses primarily on the processes of exchange and negotiation (upon which most of my work is built) visualising the threshold between selves through which exchange takes place, as a porous membrane. The *Oxford English Dictionary* defines membrane as ‘a pliable sheet-like structure acting as a boundary, lining, or partition in an organism’. An organism might be seen as a collective entity, the body politic, as much as an individual. The skin might be envisaged as a membrane between interior and exterior worlds, the scar a membrane between visible and invisible injury, the face not a mask concealing the self, nor a mirror reflecting the other, but a membrane between self and other. A membrane is also a material through which liquids pass via osmosis in a growing plant. A membranous space therefore is a space where boundaries are delineated but not necessarily visible; a space through which entities pass freely backwards and forwards; it might be a space within which breath mixes, imaginations meet, language and emotion interweave, a space into which we step with every social act, with every phrase which leaves our lips and every sound we hear. Examining the capacity of images to transform space into a membranous material within which the possibility of meaningful two-way exchange is enhanced, is a key aim of this chapter. It underpins my fine art practice and my approach to interdisciplinary research. It is a focus of the film, **duet for pain** emerging out of it, and is intrinsically embedded within any analysis of the effects of using the images/PAIN CARDS during the recorded consultations which makes up the bulk of this chapter. It supports my hopes for fluid two-way exchange to become normal practice within medical dialogue.



Fig. 60

# CHAPTER 3: ANALYSIS

## INTRODUCTION:

This chapter is primarily a chance to assess and analyse visual material and research data gathered over the course of the **face2face** project in relation to its original hypothesis that visual language can provide an alternative and more effective language with which to communicate pain, attempting to understand the mechanisms by which it does this. The exploration has been expanded to include an examination of the intersection of visual and verbal language and the ability of images to re-invent and reinvigorate both, emerging as a key notion during the project. Referring to language not as a neutral objective vehicle but as an active process bringing new worlds into being, Luce Irigaray writes: *'Patience is imperative: the future is not defined here by the past, and the house, notably of language, is not yet built'* (Irigaray 2008, p7).

This chapter aims to reveal something about how the house of language is constructed within the consulting room, and what ways photographs of pain modify this 'house', intervening in its construction and facilitating movement through its thresholds. (It is interesting tangentially to remember that the house metaphor was referenced in the previous chapter as a 'house of pain' by Susan Sontag (Sontag 1964), see page 108).

The thesis has become increasingly concerned not just with the role of images in interpersonal communication but the ways in which they intersect with and impact on language. Irigaray suggests that it is respect both for the other and for the self which allows speakers to enter the communication process successfully. By disorientating both speakers through moving dialogue away from conventional patterns, images force spontaneity, moving both speakers into a direct relationship with themselves as well as into a negotiated relationship with the other. It is possible that effective exchange relies not only on hearing the other, but equally on hearing the self – ie accepting the genuine rather than the performed self. Images have the potential to provoke such acknowledgement.

In response to current pain theories discussed in chapter one (Charon 2005 a, Wiech 2008, Gundel & Tolle 2005, Wiech & Tracey 2009 ), which argue that emotion affects pain processing and identify ineffective communication as one of the main reasons for inadequate treatment of pain (Kimberlin 2004, Yates 2002), this chapter draws on visual and semiotic theories discussed in chapter two (Barthes 1997, 1980 & 1993, Berger 1980, 1982, Burgin 1982, 1999 and 2010, Bate 2009) to unpick and evidence the specific ways in which photographic images and image making processes are able to expose emotion, make explicit issues of interpretation, signification and representation, and expand and democratise dialogue.<sup>1</sup> They can be seen as acting as mediating spaces between patient and clinical perspectives. Borrowing from other disciplines, where useful, such as anthropology (Gell 1998, 1999, Martin 2003) and discourse theory (Wetherell 2001), the chapter examines ways in which inserting images into dialogue disrupts the normative patterning of language, encourages more negotiated dialogue, improves rapport, and brings new information into the consulting space.

Alfred Gell's notion of the art object as relational (Gell 1998) provides a key insight into the way images work in social spaces such as the consulting room or the workshop. Handling, viewing and responding to the pain cards could be viewed as performances of identity construction and relationship building. Borrowing from discourse theory can help unpack some of the ethical and meaning-making complexities of medical dialogue. If we understand each spoken utterance as a social act, we can also understand each gesture as a social act. In both the recorded pain consultations and the workshops for artists and patients to attend together, images and the image-making processes become players in a dance of dialogue, transforming the patterning of utterances, and refocusing the exchange. The images and/or the image-making processes become social actors with social agency and part of the motivation for this thesis is to attempt to understand this agency.

The analysis at the end of the chapter provides evidence for the ways in which the language of both clinicians and patients is affected by the PAIN CARDS. There are few areas where language is as important as in chronic pain; it is currently the main route through which diagnosis happens. *'What is treated in pain is the misery that can only be reported by the sufferer'* (Charon 2005, p 37). The analysis seeks to demonstrate how images influence language to become

richer and more detailed and how the images act as catalysts for in-depth discussion of emotion and loss. The work of many scientific pain researchers, such as Irene Tracey, discussed in chapter 1 (Tracey 2005, Wiech et al 2008), indicate that if these emotions can be modified there is a likelihood that intensity of pain can be reduced. Pain and emotional processing use the same pathways and neurotransmitters and are increasingly shown to impact on each other (McMahon 2006, Carr et al. eds 2005, Wiech & Tracey 2009). It follows that eliciting discussion of emotion not only reduces isolation but is pivotal to increasing understanding of its effect on pain experience, reducing its intensity and thereby relieving suffering.

## **Methodology**

**Face2face** has been a broad and complex project with many different strands. Fragments of material from each strand will be selected to examine phenomena which forward the hypothesis and those which counter or problematise it. Unexpected results, 'outliers' and paradoxes will be commented on and used to inform research questions for future study.

To recap, a brief overview of the project follows:

- 1) Art workshops for clinicians and patients to attend together delivered in association with the National Portrait Gallery (NPG) between October and December 2009.
- 2) The co-creation of images of pain with facial pain sufferers at different points of their journey as they progress through pain-management.
- 3) The integration of a selection of these images into a pack of Pain Cards for clinical use.
- 4) Research into the effect of using these cards within NHS Pain Consultations, video recording their clinical use by a variety of different pain specialists
- 5) The creation of a new film exploring experiences of having and treating facial pain.
- 6) The development and delivery of a new exhibition reflecting the process and outcomes, alongside interdisciplinary events, shown at the Menier and the UCLH Street Galleries, London, between July and September 2011.

## **STRAND 1: ART WORKSHOPS**

### **Workshop aims**

The aim of the workshops was to bring together patients and clinicians experiencing or treating facial pain to participate in the practice of drawing, painting, photographing, looking and discussion within portraiture. Dislocating them from the normal clinical environment in which they meet and removing the possibility for standardised interrogative-style dialogue, the purpose was to see in what ways this shared experience of looking and image-making could promote mutually beneficial discussion. Could it reveal or expand issues significant to pain experience, but not normally discussed in the clinical setting, such as power relations, the gaze of the other, resistance to the other and disconnects in language and communication? Through collaborative exercises could these discussions promote an expansion of the boundaries of pain discourse? By examining the collaborative image-making process as a form of conversation could it reveal some of the mechanisms of dialogue applicable to the consulting room? Could it expand our notion of portraiture?

### **Workshop methodology**

The workshops were advertised to clinicians and patients with or treating head and/or facial pain. Although each of the four workshops was self-contained they were designed as a series with participants encouraged to attend more than one. They involved a mix of looking at and discussing images within the NPG's unique collection of portraits as well as new exhibitions, for example the Chasing Mirrors Exhibition,<sup>2</sup> and slide projections of photographic portraits from the nineteenth century medical portraits of Charcot, Diamond and Duchenne to the fine art portraits of contemporary artists such as Goodwin, Wright, (discussed in chapter 2) and Ballen. The workshops explored changing notions of the gaze, the photographic exchange and the power dynamics within both medicine and photography, highlighting their potency when combined. All the workshops were audio-recorded and transcribed. As with every other part of the project participants were anonymised by being given a study code which ranged from letters A to Z with a numeral eg T1, W5 etc. Evaluation forms completed at



the end of each session indicate the impact workshops had on catalysing debate around the face, pain, the portrait, and the difficulties of exchange with another. The material was examined using a mixed methods approach as defined by Creswell (2004) allowing us to analyse the basic quantitative data retrieved from the demographic and closed questions, link it with the qualitative data produced by the open questions and along with analyses of the workshop transcriptions identify key notions emerging.<sup>3</sup>

### **Analysis of workshop material**

The integrated analyses of the transcripts, evaluation form and video footage from the workshops is revealing, but although supporting the general hypothesis of the thesis it is not its main focus. For this reason the quantitative and qualitative analysis of the material has been placed in the appendices, and can be found on page L in volume 3, appendices.

## **STRAND 2 :CO-CREATED PHOTOGRAPHS**

### **Aims**

A key aim of co-creating images of pain with sufferers was to develop a collection of pain images which could form a pack of PAIN CARDS, offered as a new communication tool for clinical use. With these images we hoped to create an alternative visual language for pain, which could overcome some of the difficulties associated with its resistance to verbal language. By acting as catalysts for dialogue the images aimed to address the limitations of pain discourse in the consulting room. In making pain visible we hoped the images might not only improve trust and 'believability', but initiate a process of 'recognition'. Pain has a past, it has a present and a future and frequently when these are hidden and disintelligable within a person's memory and history they interact with each other, in my belief serving to intensify and complicate the pain experience. There is good evidence to show that fear of pain increases pain whereas optimism reduces it. Neuroscientists such as Wiech and Tracey (2007)

describe pain as '*an interpretation of the nociceptive input influenced by memories, emotional, pathological, genetic, and cognitive factors*', (p 377). If pain can be externalised within an image, the hope is that some of its strands may be disentangled and moved to a place within conscious control, so reducing pain's hold over the sufferer. An important aim of the co-created photographs was to catalyse this process bringing what is sometimes seen as less medical but which is directly relevant to pain intensity and prolongation, into the consulting room.

Wiech and Tracey conclude that the '*resultant pain is not necessarily related linearly to the nociceptive drive or input; neither is it solely for vital protective functions. This is especially true in the chronic pain state*' (2007 p 377). In acute situations pain is a vital warning signal protecting from death and further injury. With chronic pain the system and its processing have gone so wrong that although physiologically it is very unlikely to lead to death, the experience of it, for so many sufferers, is a catastrophic assault on the self, almost tantamount to death. One way of breaking this cycle of catastrophe and aversion, so natural when experiencing intense pain, but so damaging to the person in pain, is to extricate it from within the confines of the self and put it, via an image, into a public space where it can be discussed and reframed outside fear's vice-like grip.

## **Key notions**

The images work in several ways: metaphorically, literally and sometimes relationally and corporally. Fear, loss, fragmentation, isolation and alienation, are key issues emerging in discussions resulting from their use.<sup>2b</sup> Additional themes surfacing are medication as a contested issue, feelings of being half a person, of splitting, of not being believed, of being a 'shadow' of the person they used to be, changes in self image and loss of identity, and pain as a negative or disintegrating/decomposing process. The threads emerging through the images generally convey a sense of something going wrong, processes of loss and chaos, for example: the mirror is fragmented, the buildings are disintegrating, the fruit decomposing or pierced, identities are torn, medication overwhelms and buildings which should heal contain objects of fear and words which confuse. This is almost a literal reflection of what has happened in chronic pain and its

perception; the pain system has gone wrong, and the language chosen to describe it is that of physical tangible damage.

Notions of interpretation and negotiation are central. This section analyses a selection of the photographs revealing the multiplicity of interpretations they elicit and their potential to improve empathy in a clinical setting. Photographs are polysemic; each image forces us to negotiate our interpretation, which can pave the way for a more negotiated democratised dialogue. The chapter will analyse selected images through a variety of means focusing particularly on metaphoric and semiotic analysis, with two important caveats. One is that the most relevant interpretation to the consulting room is that of the individual pain sufferer, and it is this that the images aim to expose. The second is that although many of the images work metaphorically it is not the only way in which they are functioning; they have a materiality and a relationship to the people handling them and making them.

## **Methodology**

The methodology for creating the images has been discussed at the end of chapter two in detail and will not be repeated here, except to emphasise that the collaborative process was an essential method for avoiding re-appropriation of the pain of another, intensifying the inevitable in-balance of power. All participants, as in other parts of the study, were given codes for anonymity, such as I1, I2 etc. All the images were co-created in one-to-one sessions between myself and facial pain sufferers, lasting between one and a half to two hours. They were held mainly in rooms in the hospital but occasionally, where appropriate, in locations chosen by participants. The purpose of the workshops was to co-create images which, as closely as possible, represented the pain sufferers' unique experience of pain. All workshops were audio-recorded. The sessions (numbering between nine and twelve) happened at three points during their treatment journey; before, during or after management/treatment in order to prevent them from being trapped not just within their pain but within a single negative image. By working with sufferers at different points in their management journey we ended up with a collection of images reflecting a broad range of intensities and pain qualities. This arc of time allowed us to represent changes sufferers had made in their perception of pain and to reflect a sense of

movement and transformation, where present. It was a way of addressing the sense of stasis and paralysis so often accompanying the language and experience of chronic pain states and a means of eliciting pertinent narrative and significant emotion to surface to be discussed.

### **Translations and relations**

The photographs are translations of pain states; translations of ephemeral feeling into concrete visual objects. As material objects they become embodiments of pain with physical resonance within the consulting space. They also become relational in the sense described by Alfred Gell (1998) creating connections between dialogue participants as well as between the emotional and the sensory; the mind and body. In a sense they stand in for the 'body in pain' as a reminder of its corporeality and bring this into the centre of the consulting room and its language.

Many of the images share aesthetic qualities, which may in part be the result of my own involvement in the image-making (which was a constant), but they also indicate qualities inherent to the pain experience. There is a bizarre nature to many of the photographs, which reflects the surreality of pain, forcing us to turn to unusual combinations of elements to come in any way close to its representation. Moulding bread on an examination couch, eyes peering through a jungle of twigs and branches overwhelmed by shadow, teeth out of scale and falling through a disintegrating building, a glass full of ice, scalpels, mirror pieces reflecting a face, a hospital entrance whose open doors contain crumbling rocks and the glint of sharp implements, fruit pierced by pins or mirror fragments, shadows within shadows, small rag dolls having a coffee near a window behind which lovers kiss, or hanging from steps in a derelict litter-ridden corner of the city (see figs 62, 63, 64, 65, 66, 67, 68 and 95). These are images which emerge from isolation and suffering, from an inability to find sufficient verbal language with which to articulate or translate it, or a framework within which it can make sense. This is a world beyond the realm of numbers, where 1 to 10 is rendered meaningless.

## **Literal and symbolic**

Many of the more literal images reflect temperature such as burning, or ice, a significant number depicting sparks and electrical currents. (The latter were frequently chosen by facial pain patients). See figs 69, 70a, 70b and 71. These fit with the consensus in the medical literature identified by Semino (2013) that chronic pain is often described by sufferers in terms of damage done to the body (Aldrich and Eccleston, 2000; De Souza and Frank, 2000). These temperature images may not tell us any more than their verbal counter-parts such as 'burning' or 'searing' in the McGill Questionnaire, but what they elicit additionally is a sensory response in the viewer (clinician). This has the potential to increase empathy and provide immediate clues to pain quality. It has been found to be particularly useful where English is not the sufferer's first language or verbal communication is difficult. There have been occasions when my colleague, Prof Zakrzewska, has been working with a translator and the images have directed them towards differential diagnoses, for example a dull aching pain is unlikely to be trigeminal neuralgia, whereas an electrical shock type pain might point in that direction (Zakrzewska communication 2011 - 13). This is something Prof. Zakrzewska is collecting data on and a subject for future research, but it is another context in which the literal images might be particularly useful.

The predominant colours in the photographs tend to be black, white, red, and occasionally yellow/orange. Black and white have strong symbolic connotations in Christian and European mythology. Black has become the colour of mourning, often also symbolising evil and objects of fear. White, or absence of colour, has also been a colour associated with death in Europe and in Chinese Opera it is seen as the colour of evil (Warner 2012). Black, White and Red are frequently found to be symbolic worldwide and are, for example, the colours used to paint the Malangan carvings, used in ceremonies in New Ireland after the death of an important person. The solid wooden 'containers' for ancestral life-force are painted with these symbolic colours inscribing their anticipated final alliances through specific painted decorations (Gell, 1998 p 226). These specific colours are highly charged within many cultures and it is difficult to see their use within the co-created pain photographs as coincidence. The significance of this is unclear but it is notable that exceptions to these choices of colour are evident in the series of images made by W5, which are atypical and circle the pain experience, rather than depicting a linear journey. Rather than progressing from

high to lower pain intensity, W5's series of images evoke feelings of transience, and elusivity, defying typicality in many ways such as choice of colour, chronological progression, content and aesthetic.

### **Predominant metaphors and their relationship to categories identified by Biro and Semino**

The majority of metaphors evoked by the less literal images are still those of injury and harm and these metaphoric visualisations provide more than pure verbal description. The photographs have size, texture, colour, shape, surface, they sit in and move across space. They are visual and not purely verbal metaphors, and in examining the predominant (and later a few of the unusual) metaphors we might ask what does this materiality add? Needles, glass and knives pierce the skin of fruit, metaphors for assault on the body, see figs 64, 65 and 95) The piercing of skin, boundary or membrane between interiority and exteriority, creating metaphoric wounds with which to represent non existent lesions or invisible causes. The knives and swords piercing the skin not only have resonance with Christian iconography for suffering, such as the many versions of the martyrdom of St Sebastian, but also have resonance with Mexican artist, Frida Kahlo, known for her depictions of physical and psychological suffering. For example plate 161 (Kahlo 1995, p 285), fig 72, Kahlo's nude body, is reduced to a simple outline pierced by arrows. Along with the shadows of the axe or dagger, the sharp implements hidden within the falling rocks, see figs 28 and 65, images conform to the category of weaponry metaphors for pain, identified by both Biro (2010 and KCL Lecture Oct 2012) and Semino (2013). In the same paper, Semino (2013) also refers to metaphors of containment and imprisonment, which are reflected in the images co-created by musculo-skeletal sufferers during the **perceptions of pain project**, but are slightly less represented in those made during the **face2face** project. This may be due to containment metaphors referencing the body, more relevant for musculo-skeletal than facial pain experience. Many of Frida Kahlo's images could be classified as containment metaphors for example plate 56 *a very sad still life* (1995 p 233), fig 73, and plates 100 and 1001, *don't come crying to me* and *yes I come crying to you* (ibid p 253), fig 74. Facial pain experience seems to generate metaphors which relate to blurring of sight and sound more than to containment, perhaps a direct result of the face as the locus of seeing and

hearing, pivotal in communication. For example image 53 (fig 75 ) in the PAIN CARDS depicts two phone receivers hanging on wires with a black space between them, suggesting a gulf between hearer and speaker, or an absence of one or both. PAIN CARD 43 ( fig 76 ) clamps the lips with a clothes peg preventing speech. Exceptions which could be classified as containment metaphors are that of a sufferer trapped behind a transparent screen separating her from the rest of the world and that of a building deteriorating.

I see the latter more as a metaphor of decay rather than entrapment or containment. Similarly there is an image of a shadow without a mouth, fig 9, where the words are trapped as there is no mouth with which to speak (and no ears with which to hear) referencing barriers to sight and sound, falling more into the category of threshold/barrier metaphors identified by Semino (2013) as evident from the top100 collocates of pain uncovered in the British National Corpus (BNC) rather than a category of containment/imprisonment .

Alongside a category of weaponry metaphors, Biro (2010 and Biro Oct 2012 KCL lecture) identifies two other categories of metaphors for chronic pain descriptions, both of which are reflected in the images produced during **face2face**. These two categories he terms the *X-Ray/Anatomical Metaphor* (such as Frida Kahlo's broken pillars within her torsau Kahlo 1995, plate 134, p 274), and the *Mirror Metaphor*. The X-Ray or Anatomical metaphor was more evident within the **perceptions of pain** images, such as the ice hand (Padfield 2003 p36, also fig 77) appearing almost like an x-ray referencing the sensation of coldness moving through the internal rivers of the body, or the leg assaulted by knives along its edges cross stitched into its contours, (fig 26, Padfield 2003 p 62). There seem to be fewer anatomical /X-Ray metaphors within the **face2face** images. Exceptions might be the portraits, most of which split into two sections, for example a face burning on one side, half a facial portrait in black and white with a single coloured flower, (see figs 78 and 79), the split positive and negative logo image for **face2face**. All of these cases it could be argued fit more naturally into Biro's category of Mirror metaphors (2010 and Biro, KCL lecture 2012) than anatomical. For me they suggest not only the physiological fact that many of the pain conditions patients were suffering from affected only one side of the face (for example TN) but the psychological schisms implicated with chronic pain. Many participants from the **face2face** project talked about the two faces of pain, the public and the private, the self as it was and is now, the

visible appearance, the hidden experience and subjective feeling. Interestingly, in Kahlo's diaries (1995) there are also drawings of split faces, for example plate 110 on page 258 which combines half a portrait of herself and half of Rivera within one image. In many of the evaluation forms from the NPG workshops participants reference the act of looking/being looked at. It appears that different perspectives, even polarised perspectives, is a pivotal theme running through the study and its images, consistent with many of the difficulties associated with chronic pain. Integrating different perspectives was, and remains, a key aim of the study and its processes. One of the things these images do is provide tangible evidence that such conflict and polarisation is central to facial pain experience.

## **Case Studies**

### **I3 Trigeminal Neuralgia pain – relived by surgery**

During *perceptions of pain* some of the psychologists at INPUT expressed concerns that patients could be trapped within a negative image of pain as much as within their pain. The clinicians at UCLH suggested that a way of avoiding this, and of reflecting positive changes patients make, was for me to work with them before, during and after management. One of the most striking images in the **face2face** collection is perhaps that of the strawberry with a knife through it, see fig 30) It was arrived at after a long process of development, involving pins, transparent screens and scalpels.

What was as striking as this image from her time waiting for surgery was the way in which she transformed the strawberry metaphor in the images created post surgery. These referenced back to the strawberry, to the pins, and even to transparent shields. This time however, instead of the pain sufferer being trapped behind a transparent screen, it was the strawberry, the pins, the hospital name tag and the drugs which were trapped within a transparent spherical ball, while the pain sufferer remained outside, containing it in her hand. From her new position separated from the strawberry and on the same side of the screen as her family and friends, I3 was able to throw away the ball, containing these symbols of pain, sending it over moving water towards the horizon. The final images reflect her experience of being pain free following surgery. Unlike the



static image of the bleeding or weeping strawberry before surgery, the post surgery image evokes light, transparency and importantly, movement. The strawberry metaphor, like her pain, has been transformed. See figs 80 and 81.

The images cannot take credit for the fact that she is now pain free - that is down to accurate diagnoses, skilled surgery and her own physiology and approach to the process. However that the image-making process was valuable and facilitated psychological movement and transformation is reflected in her words in our last session together:

*I couldn't see anything other than being stuck in that pain cycle ... I was locked in a place with this pain and couldn't move forward. I think through coming here and having a look at a beginning, middle and an end, it somehow moved me onto the next phase and psychologically I could look at it differently. I don't know, without this, how I would have moved.* (participating patient Study no I3).

## **I2 Chronic facial pain – for which there is no cure**

Not all the patients were surgical. With chronic facial pain, the expectation was not that people would be pain free, but that suffering could be reduced and pain might have less of a limiting impact on their lives. Study no I2 is a wonderful example of this, where her images moved from these of decay, disintegration and loss (See figs 82 and 83) to I2 setting up workshops for the homeless in her home town, taking over empty shops to become gallery spaces and returning to work. (See fig 56 re bridge). It is difficult to argue that it was the image process alone; it was one component in a multidisciplinary pain management programme, but in her words:

*I found it very therapeutic. It has allowed me to come from a point where I have been off work since 2003 to actually taking that step to going back to work. I think, if I hadn't worked on this, I would not have been able to have taken that step, so I feel very grateful'.*

(Participating patient, Study no I2).

When she came to the interdisciplinary symposium associated with the exhibition in July 2011, she re-asserted these sentiments saying:

*it's been a privilege for me to work on this project ... I'm really pleased that images may be able to be used in consultations so that other people who experience pain, which is ... so completely indescribable, you can't put words to but you can put an image to ... It's a very dynamic project to be involved with and I've really enjoyed it and really valued it, - I hope that it helps other pain sufferers, ... Today was quite an important day because I was finishing at another hospital ... and as I left the unit I took a photograph of the door and the sign, so I kind of recorded the end and I can honestly say that I don't think that I would be at that point of being discharged from the X Hospital had I not done this project.'* (Transcript Interdisciplinary Symposium 2011).

### **Atypical metaphors/'outliers'**

I would like to discuss a few of the images containing atypical metaphors which do not fit accepted metaphoric classifications for chronic pain descriptions and do not necessarily reflect a movement from high pain to low pain. These challenge us. According to medical anthropologist, Professor David Napier, we learn more about a society from the experience of those at its margins than from those living by its norms or within its accepted frameworks (2003 and Napier, UCL Lecture, 19.11.08.). Napier cites Frederik Barth's definition of culture as: '*An empty vessel that is defined at its peripheries, where it is contested and challenged*' (Barth 1969). In the same lecture he discussed the relevance of ways in which outsiders are understood from within, problematising the construction of specific illnesses by societies and concluding that the ways in which they do this tell us something about the prevailing categories and concerns of that society. Napier argues that the way we *assimilate 'the outside'* shows us how we also *pathologise it*.<sup>14</sup> This is an intriguing hypothesis with potential relevance to chronic pain experience. Could it be argued that chronic pain sufferers are also an example of outsiders being '*pathologised*'? Chronic pain sufferers find it difficult to fit their experience into current medical models for pain. They inhabit a liminal area where they seek a space inside accepted medical models of injury, but constantly feel displaced and excluded from

entitlement to such a place within its framework of injury and cure. This perhaps has relevance to David Biro's argument that there should be no distinction between physical and psychological suffering and pain, that they constantly intersect and impact on each other and that our definition of pain should expand to accommodate both (Biro, KCL Lecture 25<sup>th</sup> October 2012). If our definition of pain expanded along the lines Biro suggests, (see page 22 in intro) would it allow the experiences of chronic pain sufferers to move from outside the margins to inside accepted medical frameworks? Would this help resolve some of the conflicts of perspectives and schisms in agenda and language between clinicians and patients?

Correspondingly, the images lying at the edges of, or outside what appear 'normal' pain metaphors, might reveal more about the experience of chronic pain and the way society engages with it than those that fit within the commonly accepted metaphoric categories identified by Biro (2010), Semino (2013) and Bourke (2011).

### **Atypical aesthetics and process: medication – loss - alienation**

One of the co-creators whose aesthetic stands out as atypical is I2 who tore up letters from newspapers and publications to make new words out of them. The process suggests the remaking of a world post pain, alluded to in the title of Elaine Scarry's seminal work on pain, *'The body in pain: The Making and Unmaking of the World'* (1985). The process reflects a violence and de-construction transformed through a process of re-creation and re-construction. The sufferer's world disintegrates and has to be remade on new terms.<sup>5</sup> In I2's images the words are strewn either across torn sheets of newspaper or a plain back background (as in PAIN CARD 49) giving focus to the central re-made word. In PAIN CARD 49, fig 83, (selected by several patients) this is stark: 'loss'. Loss is highlighted as a central issue within pain experience, and its meaning enhanced through the physical process of cutting, tearing and wrenching which has brought it into being, the disunity of scale and font of its letters, and perhaps, less consciously, through the collision of a subjective world with that of public news circulation - the external architects of accepted facts or 'truths'. This collision of claimed objectivity and intense subjectivity underlies many medical pain encounters, as does the destruction, reconstruction and

manipulation of language. Ironically, it might be these visual images that draw attention to the potency of power relationships within verbal language use.

Another theme featuring in the less typical images is that of alienation. In ***perceptions of pain***, two large childlike legs are unable to go through a small doorway of light viewed through them (fig 4) in ***face2face*** a small rag doll is lost in the large space of a seat on the underground, alongside apparently normal people going about their business. The same rag doll has a long journey through the city, where she stops off for a coffee at Costa in King's Cross (see fig 67). For most people this is a normal activity. For the person with facial pain it is a dangerous activity. Drinking, talking, hot or cold liquid all trigger increased pain and for Trigeminal Neuralgia sufferers, a possible attack. The doll can only stare at its outsize cup of coffee balanced on its legs, while behind it, seen through the glass window separating them, a 'normal' couple kiss, exchange intimacies and embrace. The doll's figure appears outlandish and alien in this 'everyday' environment, reflecting what is an 'everyday' emotion for many facial pain sufferers. Elements of this photograph could correspond to Semino's threshold or barrier metaphors, but the overriding sense is that of isolation and alienation, both from society and from the self.

What is striking about many of the images is the negativity they indicate, at its most extreme, a fear. Fear is indicated by rocks tumbling out of control towards I4 as she attempts to close the hospital doors, or piling up like overwhelming rubble as she sits hunched up head down, or looks out from beneath the shadow of an axe, or for I2 by mounds of medication sprawling across the image or through I5's hands encircling his figure asking for help. (See figs 28, 65, and 84). The dominance of fear is supported through verbal as well as visual testimonies, for example I4: *'Currently I'm in remission, but now I have fear instead of pain. Fear of when it's going to return; apparently it always returns, perhaps in three weeks, three months, or three years. It's like the sword of Damocles hanging over you.'* (***face2face*** participant, study no I4).

In the images in both ***perceptions of pain*** and ***face2face*** a sense of being overwhelmed by pain and fear, by a force outside personal control, is very evident. It is often embodied through images of nature with a dual power to destroy and overwhelm with a force we cannot control and to create beauty and serenity towards which we reach at times of suffering.

*...The rocks depict the isolation, the feeling that you're being overwhelmed by this force of nature that one can do nothing about. You can't stop it. It's like giving birth, ... – once it's reached full-term, you cannot prevent the baby from emerging! It's the same with pain. I'm very aware that man thinks he can control nature, and of course he can't.... I like the idea of a final hopeful image, incorporating flowers I have grown, especially roses. Different cultures have various interpretations for the meaning of flowers; roses usually symbolise hope.'* (**face2face** participant, I4, see also fig 57).

Pain, like nature, is both creator and destroyer. The nature metaphors are apposite conveying a sense of being out of control, characteristic of chronic pain descriptions. Pain destroys past identity and ways of being. If the search for new ways of being in the world can become a transformative instead of limiting process, it could lead to opportunities not imagined before its onset. If the cards can elicit discussion of these aspects, could they help sufferers transform their pain into something productive and transformative rather than limiting and punitive?<sup>6</sup>

#### **W5: Resists reflecting movement from high to low pain – spirals around pain**

The most atypical *series* of images was co-created with W5. Interestingly for W5, as indicated earlier, (page ref) despite the middle sessions representing lower pain intensity and forward movement, later sessions reflected high pain levels and the less coherent and more fragmented nature typical of chronic pain narrative. Chronic pain disrupts narrative, and perhaps having that seen, heard and acknowledged is more important than trying to frame the narrative linearly. These images were atypical in many ways, not only their lyrical aesthetic, choice of colours and lack of linear progression, but in their content and multi-layered and complex metaphors. The shadow metaphor dominates many of them, presenting pain as an ephemeral substance (in contrast to the many concrete images of *perceptions of pain*). It permeates identity, it permeates the environment it is integrated into. The shadow has an ambiguity of meaning, consistent with the distinctive aesthetic of these images. In PAIN CARD 25,

shadow provides a counterpart to the solidity of the hand in fig 2. In this image it feels as though we are in the presence of different time zones, that the shadow may represent the past or the future, the self or others. In some of images multiple shadows are layered on top of each other in an attempt to create a 'shadow sandwich' suggesting a co-existence of multiple selves and multiple time frames. The shadow extends beyond the boundaries of its owner, physically and metaphorically; it is a shadow of something or someone beyond the frame. There is no shadow without an object. The shadow reminds us that pain is not a single moment, a single pinpoint of suffering, but is stitched into the rest of our lives, evolving and temporal, it has a history and a future.<sup>7</sup> For Freud our lives are shaped by our unconscious. His technique of free association aimed to access repressed experience and emotion is not wildly different from use of the images to trigger discussion of aspects of pain not previously 'owned'. For Jung, it is often claimed he defined the shadow as the personification of aspects of the unconscious personality, the un-lived and repressed side of the ego, representing not our public "persona" but that which we would rather not acknowledge. Jung has claimed that this is to misunderstand him where "the shadow is simply the whole unconscious" (von Franz 1974 p5).

Another intriguing image in W5's series is of an examination couch with a chopping board supporting moulding slices of bread, lit by an overhead spotlight, see fig 63. Light is the corollary of the shadow, it creates shadow; without it, the shadow would not exist. It is the shadow which gives depth to lit objects, without which they would be flat. To the side of the bed is a surgical trolley on which are tubes of paint, a pallet, tubes of pigment and below the trolley a red velvet scarf leading the eye off frame. Many connections are set up between: visibility and invisibility, the painting tools and the surgical implements one might expect to be there, the decomposing bread and the potential patient, isolated and small within the medical environment, pinned to the table by light and the gaze. The substance under examination is visibly decomposing. One of the noticeable qualities of these images, (and several others within **face2face**) is the presentation of pain as a negative process, the outcome of which if taken to its logical conclusion, is disintegration or death. Despite the fact that chronic pain rarely leads to death, these images remind us that this is how it is often experienced. W5's images, though far from typical and very infrequently selected by others, highlight an important aspect of pain experience - an

implicitly present connection in the minds of sufferers with decay and ultimately death. This reinforces photography as the most apposite medium with which to capture it, emphasising the importance of breaking such cycles of catastrophising and fear, which lead to increased pain.

The images have a poetry which belies their bleak message:

*It's a horrible thing, but it's like a death that comes over your life ...it's ... like a shadow or a ghost because it's transparent... it's like a shadow of death that kind of passed over, when I didn't know whether I was going to make it through, or not.'* (W5 **face2face**).

If present, it is important for such a notion to be articulated and acknowledged in order to be replaced with a deeper understanding of what is contributing to that fear, with accurate information about pain mechanisms and with hope for the future working to dispel the shadows.

## **Interpretation**

### **Pain as a shadow**

It was the shadow in this series of images that Professor Elena Semino highlighted when I asked her to write a short interpretation from her perspective as a linguist on W5's images. I was interested in where and how other people's interpretations intersected or conflicted with those of the sufferer. The subjectivity of interpretation parallels the subjectivity of pain; like pain it resonates in relation to the past as well as the present. Evidencing the different ways in which meaning is constructed for individuals through the images, provides a glimpse of the variety of ways in which significance and meaning is conferred on pain experience and the need for a flexible and negotiated dialogue capable of interweaving multiple interpretations. Your 'shadow' is not the same as my 'shadow', just as my 'pain' is not the same as your 'pain'. Images make this explicit.

*A shadow is by definition indistinct, poorly delineated and transient. In language, 'shadow' is often used metaphorically to suggest diminished abilities, power, strength or beauty, as in 'a shadow of his/her former*

*self'. The shadows in the picture suggest that the pain reduces the sufferer to something weaker, less individual, less active, more anonymous than they would otherwise be; that other people may not be able to see them and value them as they otherwise might; that the sufferer's own self-image is that of someone who is less than a full, complete individual ... The absence of colour and perspective reinforces my impression of a diminished existence (Semino 2010, Linguist).*

This is very close to the sufferer's own testimony: *'It's just a way of explaining that you really don't feel like the person you were at all... there's almost no relationship, there's such an emptiness inside of you cause you just feel completely burned, like there's an empty shell'* (W5 **face2face**). The image reveals significant aspects of chronic pain experience; the loss of identity, the multifarious impact of loss, and the existence of related shadows. The shadow is the metaphor that most people focused on when asked to respond to these images.<sup>8</sup>

A radiologist, psychotherapist, artist, writer, social worker and architect, all interpreted the shadow in different ways; however they all identified the shadow metaphor as central to the image's construction of meaning. It was the shadow that they wrote most about.

*I see the images in terms of the relationship between you (Deborah) and the patient as well as the journey of her treatment. ... In the first image she is just a shadowy figure as she has not yet revealed herself to you. In the second image she appears as a patient – the bread on the examining couch. In the third image it seems to me that she has revealed a lot about the nature of her pain – she is the pain in a sense in the form of the mouldy bread. ... (Psychotherapist).*

*The first image is of a faint shadow – a silhouette of a child or girl's head cast onto a wall showing hands raised in a manner that seems placating, defensive or beseeching. This is haunting and insubstantial. ... It suggests the soul within, rather than the substantive body. Its posture suggests that the soul is not at ease but it is difficult to tell clearly what the source of their anxiety is (Radiologist).*



*Lost, confrontational. Consumed by shadow. Again I sense the distancing created by pain. The shadow gestures differ from each other. Confusion. Feeling separated from body/self (Artist).*

*The shadow – she is almost there, almost not there. ... The shadow ever sent from stone, from bread, sinking into matter ... The gesture in shadow, the blurred disappearing form with formlessness, concentric circles of rain on water, and the eye travels upwards looking for her (Writer).*

*Is the shadow malevolent? Ambiguous, feels as though she is subjected to something ... I see a circle rather than a line, returning (Artist and Psychotherapist).*

*Pain is a powerful emotion and if present on the face it is so much more devastating. It results in loss of identity, the patient feels that her own life has gone and pain has now taken over her identity. The patient has now come to seek help from a health care professional and is hoping that they will be able to make sense of what has happened to her (Clinician).*

*The image is a representation of how the patient sees herself and also how she feels others perceive her. ... The shadow is of a woman of black Afro/Caribbean descent who portrays herself as this shadow due to a possible lack of identity. ... Racial differences are often misunderstood and mis-diagnosed by health care professionals and language can also be a possible barrier. ... (Social Worker).*

*The portrait is absent, it is spacialized through shadow ... Are these the hands of the artist, of the doctor, of the patient, I cannot tell, all subjects converge ... (Architect).*

The number of interpretations arrived at for one aspect of one image reveals the multiplicity of their potential meanings. The space between meanings could be visualised as a membrane through which exchange needs to flow both ways in order for a deeper mutual understanding to be arrived at. If we accept we don't all see an image in the same way it forces us to negotiate. If language becomes negotiated in response to the images, can it remain negotiated in response to pain? Can the significance of each individual's experience of pain be revealed through discussion of the images? What is worth noting, is that in the

interpretations above the shadow is frequently linked to notions of ambiguity and lack of resolution. These images do not depict pain resolving, they depict pain alternating and spiralling around the same issues. If pain were conceived of as a material, as artist Johanna Willenfelt proposes (2012), would that material be a shadow?

The shadow inhabits a realm of obscurity, of concealment, of absence of light and visibility, it has a relationship to an object other than itself, rather than being a tangible object; it eludes our grasp, it evokes ambiguity, elusivity and fear: it is the perfect metaphor for pain. I believe the spontaneity of the creative process allows it to reach the unconscious and via the image bring elements from it to the surface. Discussion of the images shines a light into the shadow, exposing what needs to be retrieved and reflected on.

The image as a gateway to negotiated exchange was explored at the Interdisciplinary Symposium accompanying the exhibition in 2011. For example during the discussion W5 voiced how upset she was to hear Clinician A had been using her sequence of images to convey a narrative of high pain to lower pain and/or acceptance. For clinician A the discarded bread was a good way of discussing with patients the possibility of moving pain away from their centre of focus. For W5 the discarded bread symbolised the impossibility of pain reducing because, she claimed, bread like that would never disintegrate in water. The difference in interpretive response to this image, fig 87 re-occured towards the end of the discussion when the Chair asked: *'Anyone violently or indeed even just mildly disagree with anything that's been said just to make it interesting?*

*W5 I do. I'm an artist of sorts myself ...*

*DP Were you talking about finding it difficult that other people interpret them differently from you?*

*W5 No, I don't find it difficult because I'm used to people interpreting things differently but I find it interesting what X [Clinician ] said earlier when we had a conversation, as it was a very different interpretation. I think it is different during the process of working on them... and it's only then when you are faced with an audience that you start to see the very different interpretations that other people have.*

- DP *I think that's a really interesting point... because in a way the images are versatile ... somehow if we can allow an image to inhabit a space where maybe we're just negotiating around what we understand, because you both obviously understand very different things from the same image. So, maybe that can spark some process of negotiating where you're trying to understand how each other views it, and I suppose what I wonder is can that process of negotiation have an impact on medical dialogue and medical consultation?*
- AU3 *... , I just think the whole thing is really fascinating because I think it is about opening the doors in that conversation which sometimes can be difficult, particularly if you don't speak English as your first language. And if you're very depressed and it's hard to verbalise how you feel about things, or whether you can't just mark on a scale between nought and ten what your pain is like*
- UF *Do you think again, it's about the process as well as about the end point, both of you were talking about process again?*
- CHR: *Yes, I wonder... I think your point was very important ... this picks up amazingly on Deborah's point, if disagreement about interpretation of the image is just a way of, if you like, a conversation continuing, then it would seem to underscore the idea that really what's important here is the exchange, the conversation. ... What we need is a realisation that the image is open to a number of different interpretations and for that not to be an ending position but part of the process. "*

Photographs, with their ambiguity and polysemy, open up avenues of communication which might otherwise have remained closed. The images aim to: elicit a sharing of knowledge; to expose what an individual patient *is* experiencing, and not what they *should* be experiencing, albeit in the hope that transformation is possible through dialogue. Through analysing these images my belief is growing that they reflect an emotional journey of direct relevance to pain perception and experience.

## Semiotic interpretation

A more formal way of approaching interpretation and meaning making is through semiotic analysis. According to semioticians such as Roland Barthes and more recently Victor Burgin, (both discussed in see pages 111-119) photographic 'reality' could be viewed as constructed through a discourse of codes. These codes present us with a way in to discussing the subjective reality they reference. Through analysis of what the images *connote*, rather than the diverse objects they *denote*, we can observe common themes running through them identifying central issues with which pain sufferers struggle. These highlight the significant impact of pain on self-perception and sense of self-efficacy in relation to the outside world.

The connoted message in Figure 27, made early on in the ***perceptions of pain*** project, is constructed by the juxtaposition of oversize flying or suspended medication bottles and the rubbish dump that forms the background. What is *denoted* is a collection of rubbish with some medication packets in the foreground. What is *connoted* is decay, waste, the self as rubbish, the self as a space of abandonment, perhaps abandonment of self-esteem. This is consistent with the metaphors of decay observed earlier. Privileged within that reading is the issue of 'medication'. Because the medication packets appear to be thrown across the image and are outsize, out of scale with the background, our attention is forced towards them so that we read a relationship between them and the discarded overflowing piles of rubbish behind. The reading of the image is affected by the production, by the fact that the medication packets were placed on top of the original photograph of rubbish and re-photographed, skewing the relationship of scale. The pain sufferer who created this image with me described how, when at last her medication appeared manageable and stable, someone would come along and change it so it would become unbalanced and overwhelming again. When she took this image, within her selection of photographs to discuss during her consultation with Charles Pither, he noted that she hadn't mentioned the physical site of her pain during the consultation at all. Looking at the image and the rubbish depicted she said '*that is what I need to say*'.

What was evident during the ***face2face*** project was the many overlaps of references, forms, colour, and metaphor not only within series' of images but

also between series' in the two projects. This supports the hypothesis that a generic iconography for pain could be developing. (Padfield 2011). For example, the theme of medication as a contested issue described earlier has also emerged within images in the **face2face project** at UCLH with facial pain sufferers. Compare for example fig 35 from **face2face** with fig 27 from **perceptions of pain**.

What is *denoted* is a pile of tablets and some letters torn from a newspaper; the *connoted* meaning is constructed through the relationship between the letters and the tablets as much as by form and colour. This relationship is reinforced through colour. The red pills pick up the red of the letter 'T'. The limited palette; red, black and white (laden with culturally dependant symbolism) integrates word, object and background. The letters are not any old letters but torn from a newspaper, part of the information industry. They document and authenticate, while connoting fragmentation and disruption. We are not given the whole word, the 'D' is missing from its beginning and end, out of sight and off frame. The arc of the story is incomplete, we cannot see the beginning and end of the journey; rather we are thrown right into the middle of the experience. Without the letters, the tablets scattered across the image would be just tablets, signifying possibly a route to recovery, but here juxtaposed with the word 'devastated' they take on negative rather than healing connotations. Medication, as in the previous project, is presented as a symbol of frustration and dependency, of being out of control - life-threatening rather than life-giving. The image demands that medication and its inherent power-dynamics be discussed.

Equally, we could compare Fig 36 from **perceptions of pain** which *denotes* a rotting apple with Fig 29 from the **face2face** project denoting mouldy bread. The objects *denoted* are different but the *connoted* meaning is similar. The apple in Christian mythology *connotes* a fall from grace, a framework of good and evil. It is an organic object usually associated with health, nutritious, life giving ('an apple a day keeps the doctor away') a result of growing and blossoming. However, here the organic object is decomposing, there is little nutrition, it will be discarded, rottenness or 'disease' is overtaking the healthy tissue unseen until it reaches the surface. It is not only disintegration that is *connoted* but significantly a hidden secret process of disintegration. The section of this apple also fortuitously bore some resemblance to a human profile, hence its selection. The sufferer I made this image with remarked on how:

*Pain is a concept you can look at in so many different ways. It is like an apple which is rotten from the inside. There is the central core which is the centre of the pain – which is what it would be if it were in the spine – and it comes through and affects the skin. ... you can't see it to start with until it increases and increases and reaches the skin and then people see it.*

In fig 29 the bread is *denoted*, another substance usually perceived as wholesome, life giving, a basic food, with equally strong biblical symbolism, but again it is depicted as decomposing and disintegrating, becoming part of and almost re-forming its own landscape. The facial pain sufferer I made this image with described her experience of pain as a 'shadow sandwich' - itself a powerful metaphor. Interestingly she chose to make the 'sandwich' out of mouldy rather than nutritious bread, which she had propagated between sessions. The sensation she wanted the image to signify was a claustrophobic one, a sense of being stifled. It was looking at the photographs together and comparing them that prompted her to observe that the outline of the shadow on some of them needed to be less clear; the photograph that resonated more for her was the one where the mouth was less visible. She described her experience as:

W5: *kind of stifling... feeling, merging into something... then the skin, ... is really the mouldy bit ... when it is really black, it's the kind of festering feeling in it*

DP: *I was going to ask you what was significant do you think about the mould or the mouldy bread?*

W5: *cognitive impairment, your memory not being able to function properly, and just fatigue .. ... not being able to see, like I said my peripheral vision feels a lot clearer now. Did you ever have days when you just feel dizzy or faint?... it's just the most bizarre experience when your face muscles aren't moving and, your speech muscles are going wrong and it's funny that there is no mouth there is there?'*

This exchange returns us to the various planes the image is connoted on and the importance of acknowledging them, looking at the connotation that occurs at

its reception; the meanings which come into being through language as the photograph is discussed. This takes place in at least two contexts - with myself when we review the images at the end of a series of sessions and in the consulting room when the image is viewed and discussed with treating clinicians. Additional transformations in meaning happens when it is discussed with friends and family or if used within a resource for other patients – where interpretations vary wildly as patients project onto them. I am going to concentrate on the first two contexts, reviewing the images with me and subsequently with clinicians.

W5     *A wound will only truly begin to heal itself on your own acceptance that it is there, and has been bleeding. ...*

DP     *Do you think that's where the images of the red come from?*

W5     *I don't know, I was just kind of throwing ketchup around! It probably does yes. And just kind of the harshness, of having that level of pain ...*

(transcript from 1:1 art workshop between myself and W5).

How much is this exchange affected by a willingness by W5 to agree with a suggestion I have made, which had resonance for me, but might not necessarily have for her? Issues of manipulation can and do emerge within the language used around the images.

Perhaps a more direct exchange comes later in the same session where the questions are more open and less leading:

DP     *Tell me the difference between those two?*

W5     *I think that one is where you are kind of looking into the light, ... looking up into the sun. And this one is like the jaw pain, and the pain behind your eyes, and sinus area.*

DP     *and how do both of these relate to you?*

W5 *That's the rising back above, the life that's been taken away. You know? It changes your life, but it still transforms and gives you back life, like the flower parts of it. One stem might die, but the rest lives and flourishes again. ...*

DP *There's a very rising energy to it, almost like your rising chord in the music where you suddenly go up. [referencing W5's own music she had played earlier]. Like taking action, going forward. But they are sort of joined here?*

W5 *I don't know why, I just saw a stem of a flower, and a flowerpot. I am not sure why at all. I know there's a slight sense ... of being deformed a little bit in the way the neck is, that's the way your head can end up being held with facial pain, and how you feel so uncomfortable. It's not a particularly pretty experience, but yet in a way you've still got to put your bow tie on and look pretty! Maybe that's why the flowerpot is there... It changes your life, but it still transforms and gives you back life, like the flower parts of it, one stem might die, but the rest lives and flourishes again.*

Just as I recognise in the first quoted transcript that I may have led the interpretation, it is vital clinicians resist interpreting the images themselves, and ask open questions. In **perceptions of pain** it became clear that the images were most useful when Charles Pither resisted the temptation to indulge in art criticism and allowed the images to provoke discussion of what that patient needed to talk about. The images are there to elicit a sharing of knowledge of what that individual patient is experiencing, how they *are*, and not how they *should* be viewing their experience, albeit in the hope transformation is possible through dialogue.

Much information was elicited looking at the photographs, both of physiological and emotional experience. The exchange above, in contrast to the previous quotation, allowed W5 the space to interpret the image in front of her freely. It also identified where, as a pain sufferer, she was in her journey - she had got to a point where despite continuing pain she was moving out of a difficult phase, acknowledging its presence and moving towards something more hopeful. This lends support to the suggestion put forward by some of the clinicians



participating in the earlier pilot study, that the images might be useful as assessment tools. It also highlights the multiple ways in which the images can be interpreted. If we go back to the apple image, it clearly signifies decomposition, but could it also become a symbol of potential transformation, compost which could allow new plants to grow?

Quoting Epictetus, Pain Specialist Owen Hughes (2010) asserts '*men are disturbed, not by things, but by the view that they take of them*'. I would agree with this but endorse cautiously the way he describes using images as a way of helping people to manage their pain, (with patients at Bronllys Pain Management Centre in Wales). Acknowledging we all understand 'pain' differently he goes on to assert that: '*If you can change the image you can change the experience, and this can have a very powerful impact. It is a very useful source of healing if we can give people a more adaptive meaning to their experience.*' (2010 p 48).

What power dynamics are at work within the intention to '*give people a more adaptive meaning to their experience*'? This touches on the critical necessity of artist and clinician recognising their own roles in the construction of meaning. If images change in tandem with a person's changing perception of pain, the feedback can be very powerful. However if the process of interpreting and transforming the images is not led by the patient in dialogue with the viewer (here the clinician), then conflict over interpretation can become yet another manifestation of loss of control. An unequal balance of power, almost inherent in the doctor-patient relationship, can easily be reinforced through the power structures at work within language. The reviewing of images has to be cautiously navigated and used to stimulate open negotiated dialogue. The process, if it does re-visualise or re-present a patients' experience, should not be done *for* them but *with* them, directed by the sufferer at his or her pace. Then, and only then, can the images be seen as cathartic and real transformation take place.

### STRAND 3: PAIN CARDS

At the beginning of the Interdisciplinary Symposium at the Menier Gallery (July 2011) the Chair, Dr Brian Durrans, drew our attention to the two extra senses Japanes Culture identifies, in addition to our usual five; *a sense of movement* and *a sense of the other*.

CHAIR: *the conversation drifted onto the sensorium, ... and there were the Aristotelian five senses ... hearing, sight, taste, touch and smell. I asked my Japanese colleagues if they felt comfortable with that as a fullish description of the human sensorium, and most interestingly, my main colleague said, no he didn't think that was enough, there were two more he wanted to draw our attention to ...*

*One is a sense of movement, distinct from the Aristotelian five, and the other one, ... which I think most relevant to this project, was the sense of the presence of other people, or another, - the sense of the other.*

If these two senses are paid attention to in the clinical encounter, the dialogue is likely to become more fluid, encourage psychological as well as physical movement, and privilege hearing and understanding of the other over speaking oneself. This correlates with the medieval view of the sympathetic nervous system which viewed my feelings as well as your feelings as part of the same sympathetic nervous system - not so far removed from current mirror neuron theory (see Rizzolatti & Sinigaglia 2008). What it reminds us, is that effective exchange requires movement, ie a shifting of positions in response to the exchange and a sensitivity to and understanding of the other speaker. The PAIN CARDS appear to encourage both, stimulating more democratised dialogue.

#### Aims

This part of the study used a selection of the co-created photographs to produce a resource of PAIN CARDS as a potential new communication and/or assessment tool. The aim was to assess the difference these cards could make

to clinician-patient dialogue when piloted in chronic pain encounters within the pain management teams at UCLH. For example did the images influence the language, improve/reduce rapport, affect the power relations and/or the patterning of speaker and listener, did they elicit new or different information, change the content, or affect the texture of interaction?

## **Methodology**

Consultations using the PAIN CARDS were video-recorded by moving the clinics of ten clinicians over to the UCLH artificial hospital in the UCLH Education Centre. Clinicians and patients were aware they were being filmed, all having received information leaflets and signed consent forms. However the discrete nature of the cameras in the artificial hospital meant participants soon forgot them and we could achieve as normal as possible consulting conditions. The study was divided into a **baseline group** of consultations where no images were used, involving ten clinicians from a variety of disciplines within pain medicine who on average saw two patients each. The term **baseline group** will be used from now on to describe the clinician/patient encounters which formed this control group, where patients had not been given any images to look at and whose consultations were identical to those taking place in the normal hospital setting.

The same clinicians returned a year later, to take part in the **study group**, a second round of consultations (but with new patients, again on average two each). This time patients were given the PAIN CARDS (a pack of 54 photographic images of pain) in the waiting room approximately 20 minutes before their consultation. They were asked to look through them and pick out up to six they felt related to their pain, to take these into and refer to them within the consultation, if they felt it helpful. 100% of participants found at least one image, some selecting up to 9 or 10. The term **study group** will be used from now on to describe the clinician/patient encounters which formed this group where images were inserted into the consultations.

After the consultations in both baseline and study groups, clinicians and patients completed evaluation forms independently, returning them in sealed envelopes. (See Appendices iv and x). These have been transcribed, analysed and

compared with the consultation video-recordings and video-transcriptions. This section uses a mixed methods approach to analyse the material collected. It borrows from discourse analysis to highlight specific ways in which the images affect the patterning of language, and from anthropology, particularly the ideas of Alfred Gell to explore their relational impact and agency in a clinical context. Along with a semiotic analysis of a selection of the images these approaches are inserted into observational notes of my own from reading the transcripts and watching the recordings which make up the bulk of the analysis.

### **Key issues**

The overwhelming difference the cards made to the dialogue is in the detail and depth of description of both physiological and psychological suffering, evident in both clinician and patient language. The vocabulary of both groups expands, becoming richer and more detailed, and new information is elicited including detailed discussion of emotional experience, absent from many of the base line consultations. Issues of power, manipulation and styles of discourse, such as changes from interrogative to conversational style emerge as key themes, along with observable changes in rapport demonstrated through body language and use of space. Whereas in most of the baseline consultations the physical space between patient and clinician remains passive and empty, in the study group, both clinician and patient frequently inhabit and animate it, resulting in an interweaving of limbs which spills over into a more equally woven dialogue. The performed nature of clinician and patient roles is apparent and the language of the clinic as much as the space itself emerges as contested, making visible the power struggles enacted within it. The patterning of roles of speaker and listener, and attempts to vie for control of the role of speaker appear mediated via the images. The polysemy of the image renders interpretation and representation, and the way these are both negotiated equally key notions.

### **The consultation as a discursive space: contestation**

The consultation is a discursive space where competing representations vie for acceptance and authority. It frequently becomes a contested space, which the images aim to mediate. Could the PAIN CARDS encourage the space to

become more a membrane for two-way exchange than a battleground, weaving the threads of competing perspectives into a new integrated fabric? Within discourse it is easy for certain groups to mobilize meanings so that some interpretations become more dominant than others (Wetherell 2009). In the clinical setting this is usually the clinicians', supported by the weight of medical authority and language. Control over discourse is a vital source of power, and often this is weighted against the patient. The images are one means of democratising this process. For example, in the baseline consultations, without images, clinician H uses an interrogative style of history taking, obtaining yes/no answers. In the study round of consultations, using images, the dialogue patterning has become more equalised, clinician H's questions are woven into the patient's answers referring back to his or her language, eliciting much fuller information and changing the rapport. The patterning of utterances is noticeably different.

Meanings are fluid and can be reworked to resist domination (Wetherell 2009), so the relationship between power and discourse is pivotal in the consulting room, though not necessarily acknowledged by its actors. Pain, through its resistance to language, becomes inevitably caught up in this politics of representation and attempts at linguistic dominance. The use of the image cards is an attempt to return more control to pain sufferers, making them more powerful actors within the politics of representation.

Discourse researchers make us aware that we use language not just to communicate things, but to *do* things. We construct truths and realities via language, and the growing body of social science research around language reveals the ways in which these emerge. Searching the material gathered for some of the features of interaction which discourse analysis identifies, helps pinpoint more precisely the influence images are having on the clinician-patient exchange. Some of these are: turn-taking, interaction order, footing, and stake-inoculation. Turn-taking was managed very differently when the images were being used, as demonstrated by clinician H in particular, but to some extent by all of the study group. The term footing comes from Goffman (1983) and refers to positioning, ie speaking as an author, as the 'principal' or person the words are spoken about, or animating someone else's words. 'Stake inoculation' describes ways in which speakers inoculate against the appearance of having a vested interest at stake within a version of events they want to present as

authoritative (Wetherell 2009 p 21.) An example of stake-inoculation is seen within the following short extract where PA1's use of stake-inoculation employs the dentist's advice that she see an occlusion specialist, instead of directly asking for this herself at the beginning. It could equally be seen as an example of manipulation. Early on in the consultation PA1 says of the dentist: '

*he did something to my jaw and he said my bite was out, and he started to manipulate and move my jaw....Now even though it hurt, I felt relief. ...I'm not a doctor so I don't know ... I told him what I am saying to you ... when he actually pushes this back, or makes the correction, that feels nice ...*

She carries on giving weight to the argument through it being the opinion of someone other than herself, here the dentist. Clinician A does not go along with this, so PA1 has to get more direct '*what a load of bollocks! I want somebody to come and put my jaw, to do what that dentist did ... and then I won't have any pain*'. Here she has to own the argument which has been set up previously not as her opinion but that of someone with medical/dental authority who she is quoting. Quoting advice as the dentist's and not her own works as stake-inoculation. It removes an appearance of vested interest in finding a mechanical explanation. She reinforces this by frequently denigrating her own right to an opinion with phrases such as: '*I am not a doctor so I don't know*' or '*What is an occlusion by the way?*' At the end of the consultation when clinician A asks her what she would like from her, PA1 says:

*OK recommend that I get a dental referral, to see a jaw specialist ... that looks at my bite or something, or whatever that was what the dentist did'*  
(line 1074 PA1 transcript).

There is a sense that this has been the underlying agenda for her from the beginning, whilst the agenda for the clinician has been to give a more psychogenic explanation of PA1's pain, such as hypervigilance and tension; there has been little meeting of perspectives.

Explanations for pain are often contested (not only between patient and clinician but sometimes between clinician and clinician) and the vehicle through which different interpretations compete is language. Clinicians themselves have

varied views and a patient might prefer to believe one clinician over another. Expert clinicians describe this as a cause of frustration, particularly when it means patients' beliefs, in their view, have become stuck and entrenched, as in the example above where clinician A asserts that she '*knows*' *occlusion does not cause pain*'. A way of mediating between perspectives is through democratising the language and one way of doing this, is through inserting images into it. This section explores what happens when images are inserted into language.

In the clinical setting, Wetherell's question '*who speaks when we speak?*' (2009 p 24) is critical in terms of power dynamic. Clinicians often draw on other medical voices, on the authority of accepted medical expertise and 'knowledge' which is difficult for patients to contest; patients draw on their knowledge of their own body and their subjective experience of suffering as well as that gleaned from other discourse communities such as support groups and online forums. Wetherell argues that '*to communicate at all, we have to draw on accepted and conventional images, ideas and modes of talking about ourselves and others*' (2009 p 23). The problem with pain is that there are few adequate conventional images or metaphors on which to draw, so new metaphors have to be made in each interaction. The patient's body of knowledge, the patient voice, is often given less credibility in a clinical setting, and another use of the images is to lend validity to that voice, to individual subjective knowledge of pain and its impact, and to involve the patient in the generation of new language with which to discuss pain. In this way the images are generating verbal as well as visual language and this is perhaps one of the project's main values. When Wetherell concludes that discursive practices raise '*profound debates about power, agency, the nature of subjectivity and contestation*' ( 2009 p 26) she could be speaking of pain itself.

### **Pain cards as relational objects**

It is not only the verbal language which is changed by the pain cards but the body language and use of the physical space. There is a triangle of the desk which is hardly used in the first round of consultations, remaining a passive space. What is noticeable during the second study round using the PAIN CARDS is that this space is often animated, patient and clinician both straying

into it, their limbs and body language mixing rather than remaining separated and boundaried. The mode of interaction spills over into their verbal language. The materiality of the cards, the process of handling them back and forth, moving them in space and around on the desk, appears to reinforce the agency of the images. They act as reminders of the physicality of pain, of the body as the locus of suffering; patients frequently touching their face or the part of the body in pain or using hand gestures to indicate the quality of pain, or hiding their face to demonstrate its intensity or embarrassment it instigates, (for example in PH4 at 3.36 mins in). A relationship between the materiality of the image as a translation of invisible pain and the physical visibility of the body as the site of suffering is initiated.

### **Alfred Gell: The Index**

The materiality of the art object has been much discussed in recent anthropological literature, but it is anthropologist Alfred Gell who developed a distinct anthropological theory of art which explored the agency of the art object, and described how art objects could be substituted for persons ie art objects could build social relations. This is pertinent to understanding the influence of the PAIN CARDS within consultations.

*The objective, therefore, is to create a theory about art which is anthropological ... My view is that in so far as anthropology has a specific subject-matter at all, that subject-matter is 'social relationships'.*  
(Gell 1998, p 4)

Gell argued that social agency can be exercised by things as much as people. For Gell, the 'other' in a social relationship therefore does not have to be a human being. It is observable from the consultation video-recordings that the pain cards are influencing social relations, they are relation-building. Their handling alone forces speakers to interact with each other, to use the physical space between them. The movement of both speakers' limbs become caught up in a dance absent from most of the base line consultations. (Clinician H with patient PH4 10' in, is a good example of this). Gell believed that aesthetic properties cannot be abstracted from the social processes surrounding their use in specific social settings, ie they cannot act independently from their social



contexts. With the photographs we co-created in **face2face** these social settings are several, effecting various social relations; there is my relationship with the co-creating pain sufferer, (it could be said there is also the sufferer's relation with their pain), there is their relationship with clinicians using the images, and there is the future life of the images when they become PAIN CARDS and are used by clinicians and patients with no hand in making them to facilitate discussion of pain.<sup>9</sup> It is with this context that we are concerned in this section. I disagree with Gell's apparent rejection of a semiotic approach to visual images, and assertion that images are not signs with 'meaning', that they do not form a separate 'visual language' (Gell a 1998, p 6), his antithesis to seeing images in any way as 'texts', partly as I am attempting to create just that - a visual language for pain through my practice and research. However Gell's emphasis on the '*agency, intention, causation, result and transformation*' (Gell 1998 p 6) possible through images is insightful to this study.

*I view art as a system of action, intended to change the world rather than encode symbolic propositions about it. The 'action' –centred approach to art is inherently more anthropological than the alternative semiotic approach because it is preoccupied with the practical mediatory role of art objects in the social process rather than with the interpretation of objects 'as if' they were texts. (Gell 1998 p 6).*

Semiotics is a valuable system with which to examine how the images construct and communicate meaning, as discussed earlier, but there are aspects of Gell's theories which shed an alternative light on how the PAIN CARDS are functioning within the clinic. I would argue that the integration of both perspectives, alongside aspects of discourse analysis can reveal ways in which the photographs are functioning more successfully than through the adoption of one theory alone. The PAIN CARDS appear to be mediating not only dialogue and narrative but social relations, and in this sense they could be said to have agency, to be acting as persons or 'social agents'.<sup>10</sup>

The physical and metaphoric space between speakers could be seen as being traversed by the photographs as agents. They animate the space between clinician and patient - not only in a literal sense, as will become evident in the following analysis of selected consultations, but also metaphorically. Gell argues that the aim of anthropological theory is to make sense of behaviour in the context of social relations (1998 p11). In the context of the bizarre behaviour

sometimes characterised as pain behaviour and the skewing of discourse and relations which can have happened by the time a pain patient reaches a pain specialist, Gell's theories seem pertinent. In a sense their anthropological approach might help us untangle behaviour and dialogue which can seem irrational but which has a cause and effect, in a similar way to psychologist Christopher Eccleston's framing of pain behaviour as a normal response to abnormal experience (Pain Society Key Note Lecture, Liverpool April 2012). Behaviour in response to pain is unlikely to be completely irrational or without cause; within it there are likely to be normal responses and reasonable causal links, whatever methods can illuminate these are valid to pursue.

Gell claims we make inferences from art objects or what he terms 'indexes' in the same way as we do from people, for example '*smiling "meaning" friendliness*' (1998 p 15). When we see a picture of a person smiling, we respond in a similar way '*because the appearance of smiling triggers a (hedged) inference that (unless they are pretending) this person is friendly ... we have, in short, access to 'another mind', ... the mind of a well-disposed person*' (1998 p15). In a similar way, the pain cards are indexes of pain, they are images from which we make or 'abduct' inferences and which give us 'access to another mind'. In defining 'index' in relation to art objects, Gell stipulates the '*index is itself seen as the outcome, and/or the instrument of, social agency*' (ibid p15). The pain images qualify on both counts as the outcome of a visual process and an instrument within the consultation of social agency. They are physical signs from which we infer something beyond their material reality. It is with the inferences that we wrestle and negotiate. The image cards are indexes of another individual's personal experience of pain, and what they infer from the image may be quite different from what we infer, raising notions of the complexity of meaning-making. It is here where patient and clinician are pulled into negotiation around the experience indexed, in order to draw out what is significant to the person in pain. The process can reveal more than the pain sufferer initially recognised, building a different type of language with a more collaborated texture.

## Analysis

The aim for the cards was that they might become 'agents' for initiating a more collaborative dialogue with a more 'democratised' (Bleakley et al. 2011, Marshall & Bleakley 2013) texture as well as for revealing emotional components, often omitted from medical dialogue. The quantitative analysis provides tangible evidence that this is happening. It also identifies the images which were most frequently selected, providing key information for refining the resource further as a communication tool for the future. For quantitative studies the numbers are small so it is necessary to be cautious of making too great claims from them, however the results are integrated and compared with findings from the qualitative analysis and the numbers are larger than most comparable qualitative studies (N= 80). Together both methods reveal: aspects inherent to pain experience which benefit from being discussed in the consulting room; ways in which the language and body language in the clinic and in the post-consultation evaluations is affected by the images and emerging questions, themes and codes with which to approach future in-depth analysis.

## Quantitative findings

### Image selection

The surprising result is the images which were selected most frequently. Rather than the ambiguous photographs, which would allow patients to project their own interpretations onto them, it was the more literal images which were selected most often (more than 5 times out of a possible 19). See figs 88 b,c,d,e,f,g,h,i, and Appendix T page Lxxxvi. This correlates with findings from use of the McGill Pain Questionnaire where simple words are selected more frequently than unusual ones. For example when the McGill is used by clinicians within this study '*aching*' is frequently selected but '*lancinating*' never. Personal communication with linguist Professor Elena Semino (Semino 2013) demonstrates she has observed the same phenomenon in the completed McGill Questionnaires she was sent for analysis by my collaborator Professor Zakrzewska. This could indicate the images (and McGill descriptors) are being selected for their legibility as much as the pain characteristics they depict.

However it needs to be remembered that these images were not selected on their own, but alongside less literal images which moderated and enriched their meaning. It is the images chosen alongside which allow them to evoke more complex narratives, and modify what might be literal and generalised interpretations to become more personal, and multilayered. Clinician D noted this in her feedback citing '*the relationship between photographs*' (CD3) constructed by the patient as the main impact of the cards on the consultation.

Of the eight images selected most frequently, four depict heat, and two electrical sparks. They all suggest activity; the sparks are moving/flying across the image in cards 5, fig 88c, card 3 fig 88b, and in card 18 fig 88d, the face appears as a material in the process of being burnt and in card 17, fig 88g, the branches which could be nerve endings, or branches of fire actively move up the subject's back. Pain is not depicted as passive; it is experienced and depicted as having agency over the sufferer - an active force.

Although the images might have been selected for their legibility, alternatively they could be revealing the most common pain characteristics for this group as temperature, and pain as an active and not a passive agent. Pain does not stand still, it evolves, it burns away at the sufferer's identity and well-being.

Card 45 (see fig 88i ) was selected by nearly 30% of patients (n= 6 out of a possible 19). It evidences medication which is spread over the floor like an abandoned carpet as a key issue, and through the torn words visible beneath, such as 'angry', 'disappointed', 'you'll see' 'crazy', as a contested one.

The three remaining images chosen more than five times, cards 35, 9 and 28, (figs 88h, 88f, and 88i) are all black and white photographs. These images are slightly less literal than the colour images discussed above and evoke the psychological impact of pain. Card 35 (fig 88h) depicts a hospital bed with all the technical trappings of clinical spaces such as wires, overhead lights, white sheets etc. It is a cold and impersonal space, with geometric shapes broken by numerous electrical cables. The white lettering references mathematical equations which the unintelligible words conflate not with mathematical clarity but with confusion, fear and emotion; they become symbols defying logical sense. This particular photograph evolved out of conversations with a lupus patient who described being in hospital and hearing people speaking around her but the words making no sense. It is this sterile and confusing space which

appears to evoke strong responses from other pain sufferers and elicit discussion of fear. For example in encounter PA3, 31'38" in when the patient has been hanging onto and holding back this card, the clinician prompts her to explain why she chose it, PA3 answers: '*it's about hospitals and anaesthetics, I am afraid of anaesthetics*'. The card appears to encourage patients to project their own interpretations onto it as was the case for PD4 and PK3 for whom it triggered a quite different discussion of loss.

Card 9 (88f) was the second most frequently chosen card and was also one of the three most selected images in the earlier *perceptions of pain* study. It depicts the weight chronic pain sufferers feel they are dragging around with them, but that weight can be variably interpreted. The three black and white images all elicit discussion of pain's emotional impact. The same is true of the remaining frequently chosen card, card 28, (fig 88e) a positive and negative composite face. This card has been discussed in detail in the section on the workshops (see Appendix M p L ), but it is notable that, unlike some of the other frequently chosen images, it is multilayered and ambiguous. It allows patients to discuss the perception of their pain by others as well as themselves so encouraging acknowledgement of other perspectives. It also highlights the face as a site of contestation. It reflects some of the dichotomies and dualities of pain experience, for example the chasm between the internal subjective experience of pain and its public face, the sense of a face split in half, and an identity divided, reminding us again of the mirror, and David Biro's category of mirror pain metaphors. It is images like this one which I had expected to be selected more often, but the fact that it is one of the most regularly chosen remains significant.

### **Evaluation forms post consultations**

Overall 81% patients and 88% clinicians reported that the images facilitated and enhanced communication. For these figures to be meaningful they need to be broken down into percentage differences for individual questions, and unpacked, which is where some of the surprising results are seen. Integrating these quantitative results with the qualitative analysis and comparison with existing literature and theories, will allow us to understand them better, including the unexpected results. It will reveal specific ways in which the language

becomes richer, the rapport is improved and the content expanded through reference to the images. Tables giving the raw material will be available at my viva. They would be unreadable printed at A4, so have not been included here.

Clinicians and patients were asked to rate their satisfaction with different aspects of their consultation on a scale from 1 – 6 with 1 being the lowest, (equivalent to poor satisfaction) and 6 being the highest (equivalent to excellent satisfaction). The results in figs 89 and 90 show an average answer from across the whole of the patient group and across the whole of the clinician group to each question, making a comparison of the results from baseline and study groups possible. This enabled a basic quantitative assessment of the impact images had on the consultation. Overall the average results for all patients' answers to all the questions showed a 5.5% increase in satisfaction, with clinicians' showing a 2% increase.

#### **Patient quantitative results:**

There are two striking results observable in the patient evaluation forms. One is a 17.5% increase in the study group (using images) to the question: '*How successful was the consultation in decision making?*'. The second is a 1.5% reduction in answer to '*How well do you think you can communicate your pain?*' In the context of a group where 81% claim the images improved communication, the latter is puzzling and appears to undermine the aim of the cards. It was in fact the only figure that reduced when using the images, most increases in satisfaction were reasonably high for example (rounded up or down to the nearest 0.5%). Confidence in treatment plans showed a 15 % increase; rapport, satisfaction with the consultation and clinicians' understanding of their pain all a 5 % increase. As these are well over 3 %, they can be taken as statistically significant but what remains a conundrum is the perceived reduction in ability to communicate pain. It may have been partly that difficulties of communicating pain had been raised as an issue in the project information sheets. It might also suggest that the discussions they had had of aspects of their pain using images were more nuanced and in-depth than previously and highlighted the difficulties of communication more accurately than the more generic discussions emanating from the baseline consultations (without images). Alternatively it could indicate that the cards were not helpful. A fruitful way of unravelling and

making sense of these results is comparison with the qualitative data and its emerging themes which will come later in the chapter.

### **Clinician quantitative results**

The two most striking results (also rounded up or down to the nearest 0.5%) from the clinician group are as follows: one is a 13 % increase in answer to '*How do you rate your satisfaction with the consultation?*' The other is a 4.5% reduction in answer to '*How do you rate your rapport with your patient?*' The first, if taken in relation to the patients' increase in decision-making, might suggest clinicians who feel that a mutually agreed management plan has been arrived at which their patients will adhere to, are likely to feel more satisfied with the consultation. As with the patient group all the other categories increased (except for one) with confidence in treatment plan increasing by 5.5%. The other surprising result, the only other decrease, is a 0.28% reduction (though rounded down this would become 0% so no change) in their understanding of their patients' pain. This might be a mirror result of the patient group who recognised their own difficulties in communicating pain. Here it might be that the clinicians were more conscious of the difficulties of understanding another's pain. As the language around pain and its emotional components/impact expands, patients and clinicians are reminded of the complexities of that individual experience and the challenge of communicating it through language. Another explanation maybe that clinicians felt less familiar and less comfortable with using the images and/or discussing emotions in-depth, which might have made them feel less easy and perceive a reduction in rapport and ability to fully understand their patients' pain. It might also reveal something about the nature of the questions on the evaluation forms, suggesting that these could be reviewed and refined in any future study. The cards may be acting in a similar way to Jo Spence's 'intruder' within an image, making the dialogue veer off predictable patterns, causing clinicians to feel less in control and therefore less at ease. However in a group where 88% reported that the images enhanced communication, and a 13% increase in consultation satisfaction these results, like the patients', need unravelling through comparison with the qualitative analyses and consultation observations.

## Patient qualitative results

The qualitative data from the evaluation forms was sorted into emerging themes. Many of the frequently occurring themes were similar whether or not the cards were used, such as: discussion of impact on patients' ability to function normally; carry out day to day activities, function socially and perform their role within the family. Both sets of data highlighted patients' negative self-image and negative view of their future (although there was less of this in the consultations using images). In the base-line group mostly negative views of the future were described but in the study group several patients commented on new understanding of pain providing insights which made them feel hopeful. Where new understanding had been reported in the baseline group it was more likely to be described as a new diagnosis or management, but in the study group, it is framed as a new understanding of their pain, and a confidence in the treatment plan; a subtle but significant difference. See fig Q1

FIG Q1

### Base line group

*'When the consultant told me that I may need surgery. It was significant because it was unexpected, at the same time I felt relief there was a solution.'*  
(PZ1)

### Study group with images

*'A very good explanation of the condition which has not previously been seen'*  
(PH3)

*'It was useful to discuss my pain experience in such thorough depth and following this it was encouraging to see the doctor's enthusiasm and support in steps I had already taken to manage my pain'* (PG4)

*'An improved understanding'* (PB2)

Both baseline and study data identify patients' desire to be rid of the pain, although using images this was often described as wanting the pain to be reduced rather than expecting it to go away completely, suggesting the clinicians' explanation of chronic pain had been heard more successfully. It



was also clear that patients from both groups felt listened to by their clinicians and were trusting of them. This is what makes this particular set of clinicians interesting to observe. They are from a very experienced patient-centred pain management team who all possess high level communication skills, so the results are unlikely to be dramatic. The group in our study are well aware of the implications of pain on their patients' lives and the relationship of mood to intensity and prolongation of pain. What this means is that any changes observed using the image cards are likely to be nuanced and point precisely to the specific differences the cards make rather than to dramatic and generalised overall changes in consultation quality. Had they been a less skilled set of clinicians the images might have played a different role and I would have expected a marked difference in patients' experience of feeling believed, listened to and understood. However, what we see instead, is not necessarily a difference in *quality* of consultation and dialogue, but a difference in its *dynamics* and its *textures*. Additional information is elicited and brought into the consulting room as the images appear to be generating a different language for both patient and clinician groups.

In both baseline and study groups there was clear appreciation by patients of being listened to and respect for the clinicians' medical knowledge, but what is particularly evident in the study group is the trust placed in the specific clinician they encountered. There appears a belief that they could trust the future treatment/management recommended because they trusted that particular doctor. *'I feel I can communicate with the doctor... with the GP I did not have time to say what I wanted'* (PK3) *'I feel I can rely on the doctor, I have good relation with the doctor and having a good treatment'* (PK3) This is supported by the significant increase in satisfaction with decision-making, (17.5%) suggesting that patients felt an involvement in the process, and had faith in its outcome. The relationships that developed may have become more personalised, rather than generic trust/distrust in the hospital as a whole, for example *"I feel this is the only Dr who can help me", and 'this was a good day'*. (PK3) *'Knowing that someone understands and it is not my imagination'* (P f3) *'Consultant arranged for me to have acupuncture. I have been put down for it before but it got cancelled.'* (PC3) Under the question *did anything unusual happen*, PA3 put *'being listened to'*, implying this is not usually the case.

What was overwhelmingly evident was the inclusion in the consultation of discussion of emotion, both distress caused by the pain and the effect mood can

have on exacerbating it; the possibility of emotion as partly constitutive of pain. Whereas the baseline group had expressed negative self image only two patients, (PZ1, who admitted being *'depressed'* and *'anxious'* and PH2, who described breaking down when asked about the severity of her pain), had used any emotional terms on the evaluation forms or given descriptions of emotions. Contrastingly in the study group using the images, (see fig Q2), there are frequent detailed descriptions of emotions using highly emotive words such as *'love'*, and *'hate'*, (PG5) demonstrating that the images were providing opportunities to discuss emotions and generate a richer language with which to explore their relationship to pain.

Fig Q2

*'embarrassed when my pain is severe'* (PH4)

*'when you feel you see the gap, what can you do?'* (PK3)

*'more adjectives and exploration of my emotions about it'* (PG5)

*'ground down by it, unrelenting'* (PB2)

*'relevance of the physical and the emotional impact of pain'* (PG4)

*'I'm in absolute agony'* (PC3)

*'Made me aware of how pain affects my social life'* (PB3)

These evidence a depth of discussion of emotional and affective elements rather than generic acknowledgement of anxiety or depression, *'I think the images are really valuable and helped the depth and understanding of the patient by the doctor'* (PG4). In the light of the growing evidence discussed in chapter one for the effect of emotion, anxiety and social exclusion on pain intensity, these results are significant, and suggest that the images could be a valuable tool for bringing discussion of relevant emotions into the medical consulting room.

The depth and detail brought to the discussion of the emotional aspects was also evident in the number of descriptive words for pain quality and character

which were far more detailed and specific in the study than in the baseline group as evident from Fig Q3.

FIG Q3.

<i>'eye waters and face distorts'</i> (PH4)
<i>'the stabbing and constant electric shocks'</i> (PH3)
<i>photographs highlighted the tightness I feel in the jaw area</i> (PZ3)
<i>'the burning'</i> ( PK3)
<i>'I feel I don't know my body any more because of the numbness and lack of feeling, no sensation'</i> (PD3)
<i>'Losing mental clarity'</i> (PD4)
<i>'sharpness and repetition'</i> (PG5)

Whereas some of the words patients used in our evaluation forms are present in the McGill pain questionnaire, for example *stabbing*, *tight*, *burning* and *heavy*, personalised descriptions such as *'constant electric shocks'*, and *'I don't know my body any more'* could not be included in the McGill. Along with the metaphors evident from the transcripts these descriptors demonstrate that the images have facilitated an expansion of language rather than a reduction to that of prescribed measures such as the McGill. It is the expansion of language to include aspects pertinent to an individual that the images aimed to elicit and it appears from the evaluation forms alone that this has been achieved.

The detailed descriptions emerging from the study group evaluations suggest that patients offered far richer descriptions of their pain than they did in the baseline group, but consequently their appreciation of the complexity of their pain might also have increased, which goes some way to explaining the enigma of the perceived reduction in ability to communicate their pain in a group where 81% reported images enhanced their consultation.

There were inevitably negative comments about the cards from the patient group, one saying it felt a bit forced to use them, another that the *'consultation proceeded well without the need for photos'* (PZ3), (although he also indicated

on the form he thought they enhanced the consultation) but these were very few in contrast to the positive ones. One participant admitted that he *'wasn't really sure at first about the cards but after looking closely at them I think the cards helped me describe my pain pattern.'* (PD3). Another suggested that the images *'were almost too abstract and leaned towards emotional more than physical representations, some more anatomical body images might appeal depending on the balance of origin or source of pain'* (PG4) but this patient also went onto describe how although she was using the images to describe some things she had already talked about they *'gave extra depth to my experience and added another approach to the conversation'* (PG4).

The positive effects of the cards such as: ways in which they facilitated patients' communication of their experience, helped the doctor to understand them, the improvement in rapport, the detailed descriptions of pain quality and emotional components and the way they appear to expand dialogue to include aspects which might not otherwise have been discussed, outweigh their limitations. Of using the images to describe pain, PB3 reflects: *'they allowed me to discuss aspects of it that I wouldn't normally have spoken about'* and PG4 claimed they *'enhanced both the appointment and options of treatment, extremely useful project'*.

### **Clinician qualitative results**

The open questions in the post-consultation clinician evaluation forms were also analysed for emergent themes. Many of these are similar to those observed in the patient feedback, in particular: inability to carry out normal day to day functioning and medication as a contested issue (see FIG Q4A).

FIG Q4A

<i>'the impact on her usual ability to do things'</i> (CC1)
<i>'Affects sexual function and lack of sleep'</i> (CG4)
<i>'inability to function normally'</i> (CG1)
<i>'Pictures of used pill bottles helped me understand better how he didn't want more medication'</i> (CG5)

Medication is identified, as in the patient data, as a key controversial issue for both baseline and study groups, however in the study group the images acted as catalysts for in-depth discussion of patients' views on medication and mutually negotiated strategies. Clinician G records for example that they agreed on *'non medication pain strategies'* as a management plan. (CG5)

Equally evident are observations of patients' negative views of themselves and their future (also recorded in the patient group) in both baseline and study group. See FIG Q4B.

FIG Q4B.

*'doesn't like what he sees'* (CC2)  
*'Lack of purpose in living'* (CC2)  
*'at times suicidal'* (CA4)  
*'feeling their future is only downhill'* (CD2)

These comments are more frequent in the baseline group. In the study group it is possible to argue that there is a sense of hope as a result of using the images and the discussions they triggered, for example in answer to the question *'What was the most significant moment in the consultation?'* clinician CF4 answered: *'patient saying she felt hopeful as a result of the consultation'*.

It is interesting to note that another difference between the baseline and study groups for clinicians was their awareness of being filmed; this is absent in the feedback from both patient groups. It may be that by the time they did the study group clinicians were more familiarised with the camera, but they seem slower to forget its presence than the patient group, none of whom remark on 'being filmed'.

FIG Q4C

*'I was aware of the fact I was being filmed – just conscious of it'* (CC1)  
*'Slightly unreal setting'* (CZ1)

This could indicate that the patient is used to being the subject of another's gaze in an alien environment, and it is less of a leap to being filmed. If this is so, it is a phenomenon worth noting in the clinic, another factor increasing the imbalance of power (through control of the gaze) - a notion obliquely underpinning the film resulting from this residency, *duet for pain* (Padfield 2012).

It was noteworthy that some clinicians found the question '*What was the most significant moment?*' difficult to answer, clinician G states this most directly, '*I think this question is difficult to answer*'. Generally in the baseline group their answers indicate something significant they have contributed and in the study group, something significant the patient had revealed.

FIG Q5A

Baseline group

*'My attempt to understand the impact headaches are having on her – I suspect she felt that I was truly interested in understanding her pain'. (CH1)*

*"showing photo of male perineum to explain where pain was" (CG2)*

Study group

*'the patients ability to identify and reflect on her helpful/unhelpful behaviour patterns and their relationships to thoughts and feelings (CF3)*

*'when she started crying, talking about the misunderstanding and generation gaps, problems with her children (triggered by the cards)' (CK3)*

Another difference between baseline and study group in the clinicians' data was the problematisation of different perspectives, raised far more frequently in the baseline group, whether it was patients', dentists' or other clinicians' views they felt needed challenging.

FIG Q5B

*'Entrenched beliefs and rejection of any cognitive/psychological aspects ... she felt able to tell me that I was biased (unusual for a patient to say this). A patient ... whose beliefs you cannot shift' (CA1)*

*'Psychological effects but she did not really buy into this' (CA2)*

*'Having to challenge previous doctor's diagnosis as to cause of pain as I didn't agree, felt a bit apprehensive' (CC1)*

*'inappropriate referral' (CZ2)*

As these comments appear far less, if at all, in the study group they suggest a more negotiated relationship with patients developed through use of the cards, - unless this is pure coincidence. It supports the hypothesis that the images are acting as a mediating force between different perspectives, as proposed earlier. Wetherell (2009 p 25) draws attention to an emphasis on '*contestation*' which might manifest itself in a struggle over how things are to be understood and it appears that there is less evidence of this sort of contestation from the evaluation forms completed after using the images than for the base line group who were not using images.

Clinicians gleaned new information from patients in both baseline and study groups but the feedback from the study group it is more detailed for example:

FIG Q6A

*'Awareness of source of her mood and depression' (CK3)*

*'Cognitions which are driving her behaviours "shoulds" (CF4)*

In the study group it is noticeable that the information elicited is *from* rather than *to* the patients, with the potential not only for improving rapport but understanding of pain within its individual psycho-social context:

FIG Q6B

*'Using the pictures for pain I felt him being able to show me the electric picture which conveyed something important'* (CD3)

*'Understood better her fear of going into hospital again and worries about cancer'* (CA3)

*'New information, how pain affects work and thoughts of self harm... Self-harm thoughts from images'* (CG5)

*'I was surprised by the tightness pictures being selected, .. interesting that the pain was more myalgic than from the fracture itself ... post-traumatic pain imposing?'* (CZ3)

*'picked up more of her anxiety by choice of images'* (CA4)

*'Photographs diverted the conversation from clinical/medical aspects of pain ... but usefully allowed focus on different aspect (mobility matters).'* (CH4)

The two most significant changes, (as with the patients' data), is the EXPANSION OF LANGUAGE when using the image cards, and the inclusion of in-depth discussion of EMOTIVE ISSUES. The language clinicians use to describe the quality and intensity of their patients' pain changes as much when using the images as that of their patients, becoming enriched and sharpened.<sup>11</sup> A different type of language emerges to that normally used in the clinic setting, which, it could be argued, is the most significant result of the study. For example:

FIG Q8

*'aggressive , pins and needles, like standing on hot sand'* (CB2)

*'pebbles under her feet'* (CF4)

*'dragging, pricking, splitting the body'* (CC4)

*'Half of body in pain and what it felt like'* (CC4)



*'rigid, heavy, warm, one-sided'* (CF3)

*'like a knife going into her body', 'weighing her down'* (CG5)

*'Pts life frozen'* (CS2)

In the baseline group there was acknowledgement that some patients were anxious or depressed, for example, *'Ongoing and distressing aspect'* (CE2), *'Reduce severity and frequency of pain'* (CH1) *'Emotional'* (CK1) and *'Anxious'* (CZ1). These are couched in generic terms with little reference to underlying causes or personal contexts. The exceptions to this are clinicians D and K. As a psychologist and a homeopath it would be normal for discussion of emotion to play a larger part in their practice than for other specialities, and D's observations of emotional suffering and its causes absolutely correlated with her patients' reports. It is apparent detailed discussion of emotions took place in all her consultations. Generally for all participating clinicians more detail around the causes and types of emotional pain and its impact were evident in the study group, supporting the hypothesis that IMAGES HAVE MODIFIED AND EXPANDED THE DIALOGUE. I had expected the images to open up a space for discussion of emotions but I had not expected them to affect the actual language clinicians used. For example vivid, specific descriptive words are used in the study group feedback such as *'resigned, annoyed, puzzled'* (CD4) and *'angry, frustrated, rejecting'* (CD3). This is not the language of the McGill questionnaire nor is it the type of language that appears in the baseline evaluation forms even for clinician D. The discussion of emotions using the pain cards appears more nuanced and specific to individual patients, extending beyond the pre-prescribed language of the McGill:

FIG Q9

*'loss, life ruled by medication'* (CC3)

*'I'm not usually so puzzled and shocked by what has happened to patients and how inexplicable it is'* (CD3)

*'description of feelings of depersonalisation, social restriction, guilt, communication problems'* (CB3) *(under question around effect of the cards)*

*'fearful and embarrassed' (CH4)*

*'Unbearable shame' (CB3)*

*'Photographs helped to express patients emotions in relation to her problems ...  
Started crying, her emotional problems were exposed and expressed' (CK3)*

Comments given by clinicians on the value of using the images in pain consultations I would argue validate their development as a potential communication tool complementing existing measures. A selection of these are given below.

FIG Q10

*'Not just sensory aspects but emotional effects and her dependence on drugs, site of pain' (CA4)*

*'Encouraged/enabled her to find key descriptors for her pain' (CF3)*

*'Brought words to mind for the patient' (CF4)*

*'I think she felt the images did represent her and helped her explanation' (CF4)*

*'I think it helps patients describe their experience of pain. They often complain they are not able to get clinicians to understand the impact of pain on them – photography might help them relay this better' (CH4)*

*'Could be useful in differentiating pain types (CZ3)*

*'Metaphoric connection of images to her complaint helped clarify and express' (CK3)*

*'Able to agree an understanding based on a picture' (CG4)*

*'Really enjoyed talking around photos' (CG4)*

It appears that the ability of images to expand and generate language, to expose contested issues, reveal significant emotional and psychosocial context, through their metaphoric and aesthetic content elicit relevant narrative, and

through their relational 'agency' improve rapport and mutual decision making is having a significant effect on dialogue in the pain clinic. To understand this further it is worth examining short fragments from a selection of the recorded consultation transcriptions. It is not possible within the scope and framework of this thesis to carry out a thorough analysis of all of them, but what I hope to be able to uncover is emerging codes and themes which could be used as a framework for future analysis and shine a more intense light on the specificities of the mechanisms by which the photographs are impacting on language and interaction.

### **Analysis of recorded consultations**

I will borrow some terms from discourse analysis as discussed earlier but will employ mainly my own observations from watching the recorded consultations and reading the transcripts. There are many precedents for using personal observation backed up with supporting quotations within contemporary Anthropological literature, for example Emily Martin's study of pregnant women's attitudes to their bodies (Martin 2003). The excerpts selected have been chosen as a result of findings in the initial analysis of the post-consultation evaluation forms.

### **Clinician H:**

Clinician H was adamant before taking part in the study that images would make no difference to his consultations. He is also the clinician who shows most change in body and verbal language and interaction patterning between baseline and study consultation. It makes his consultations particularly fascinating. Although originally sceptical, credit must go to him for using the images more fully than most, frequently pulling patients' attention back to them. As with all of the consultations there are inevitably confounding factors, most obviously the different personalities of patients. The study consultations also happened a year after the baseline consultations so there is room for events from the intervening period to influence. However all other conditions were kept as constant as possible, reducing the variables to a minimum.

During both baseline consultations (without images), clinician H retained complete control of the dialogue and thus of the consultation.<sup>12</sup> He fired questions to which there was generally a yes/no answer, using an interrogative-style history taking. When an answer indicated distress, although acknowledging it, generally he moved quickly onto the next question without clarifying or going into deeper discussion of its implications. It is a process at odds with the need for emotional and social aspects of pain experience to be considered medical and relevant.

*Too often have we divided the mind from the body. The two go together and it is about fusing them back together again. The functional imaging ... is showing more and more how these psychological factors are influencing pain; our perception of pain, our readiness to accept pain, and I think having some physiological basis to be able to explain to patients that these things are important and do have an impact opens up the discussion a lot more. I would consider it medical but a lot of people wouldn't as they have shut the door on the psychological aspect. I think every illness, particularly chronic illness has a psychological component. Often...clinicians don't want to go there. (Zakrzewska in **duet for pain** Padfield 2012).*

### **The space between:**

Clinician H's recordings are a good example of the ways the image cards influence use of the space. During both his baseline consultations (H1 & H2) he remained almost static, inhabiting only his third of the frame, rarely moving into the space between him and his patients. Respect for his patients was evident from the way he listened and acknowledged their answers using standardised questions around quality, frequency and intensity of pain attacks. The language was precise, using medical terminology but with little use of unusual words or those specific to that individual.

In his study consultations (H3 & H4) a distinct change is observable. He still sets the parameters of the consultation, but, for example in H4, after outlining its framework, he repeatedly moves into the physical space between him and Patient PH4, his arms and legs regularly crossing and with the photographs, animating it. At one point his legs appear almost entwined around his patient's

– a stark contrast to the baseline consultations. At 3'10", their knees are almost touching; he has moved right into the patient's space. On its own this would be relatively meaningless, it is not necessarily better for the clinician to have his leg close to the patient than far apart. What is interesting and relevant is **that the language as well as the limbs begin to interweave changing the dialogue dynamic and patterning of utterances**. Instead of clinician H asking all the questions in an interrogative-style, the patient, his wife (who is also present) and the clinician speak equally. It is possible to hear all three, but it resembles more a conversation than interrogation. It demonstrates a more democratised patient-doctor exchange such as Bleakley advocates (Marshall & Bleakley 2013).

At 3'10" clinician H says *'What I will do is get you to talk me through these cards'* and then picks up the cards holding them like a fan in his hand and lays each one on the table. At 3'15" in he asks, *'Tell me what these cards mean to you and what they tell me about your pain'*. This type of open question was entirely absent from his base line consultations, where he used consistently closed questioning.

### **The cards' agency: translation from abstract to physical**

With the cards on the desk, Clinician H gives the floor completely to the patient for the first time in the consultation, comparable to Rita Charon's description of giving the floor to her patients early in her consultations (Charon 2006). There is silence (also unusual). The patient puts on his glasses, and during the silence surveys the cards on the corner of the desk. He picks them up, running his eyes over them for approximately 20 seconds - a very long pause for any dialogue - and at 3.36 in, he starts speaking, rifling through and holding them. Marvel et al. (1999) have shown that physicians re-direct patients' opening statement after a mean of just 23 seconds, despite the fact that there is evidence that allowing patients to complete their opening statement results in increased satisfaction and improved outcomes (Robinson 2006). Here the cards have provided PH4 with a space in which to speak. There is a sense of action, the patient has agency conferred on him through the images. He has a physical response to the cards, his arms gesticulating during descriptions. The images initiate a transition from abstract description to concrete translation of pain; to visual imagery and gesture. It is perhaps not *communication* of pain that is

needed, but *translation*. The images bring pain physically into the room. Patient PH4 gestures towards his face, holding his hands around it while talking about the pain down one side, indicating how it affects him socially, '*it would affect my eating*'. His wife takes the opportunity to say at this stage '*it isn't just his face, it is everything, your back*' and uses her hand to indicate side of patient's body. The clinician discovers from the ensuing dialogue that PH4 has been shaking for many years, and appears surprised. In this more equalised exchange new information is elicited. Clinician H says they will talk about the shaking '*as it is important*' later, but they need to return to the pain. He draws the patient back to looking at the cards. There is still an element of the power-dynamic observed in the base line group, in that the clinician retains control of the direction of the dialogue when it veers off, but what is noticeable is that he signals to the patient he has heard what has been said by returning to the shaking later in the consultation. This patterning of interaction was absent from the baseline consultations where, when patients intimated emotional distress, clinician H clocked but did not discuss it.

Patient PH4 expands on how his pain affects his life; referencing pain card 13, he explains he couldn't eat or clean his teeth. His hand at this point is moving around his face, physically demonstrating the area of pain, cupping around his jaw and the side of his face. Visually it is striking. There is an entirely different dynamic and mood to this consultation than observed in the base line consultations. Patient H4 expands on the difficulties of shaving and at this point appears to be leading the discussion while the clinician listens. The roles of speaker/listener alternate, rarely occurring in clinician H's baseline consultations. Countering this clinician H maintains partial control as he is now holding the cards while the patient looks through and responds as he reveals each one. Although listening and responding, the clinician still directs when they move onto the next card, '*shall we go onto the next card then*'. The patient may have taken control of the dialogue but for some reason the clinician feels the need to hold onto the cards and retain control of the physical space.

### **Cards as a shared reference point:**

Detailed description of sensation and psycho-social context are elicited through the cards, for example card 18 elicits a description of how he can't lie down and

how it is often so painful he has to sit up in bed. Referencing card 32, clinician H asks '*what is that?*' Patient H4's hand strokes the left hand side of the card saying '*that is the pain coming down the side of my face*'. Sensation is evoked through the touching of both the metaphoric representational image and the actual physical site of the pain. The clinician asks him to expand to make sure he has understood correctly, evidencing the image has become a shared reference point, '*is that yellow bit there pointing to the pain?*' Patient H4 answers 'yes'. There is a definite democratisation in the patterning of interaction as they look through the cards and respond to each other's statements, re-negotiating to check they have understood and/or heard each other accurately. There are few examples in this extract of footing or stake inoculation (Goffman 1983), the dialogue appears to be direct, in the moment, an immediate exchange with spontaneous eliciting of pain experience. Clinician H asks another open question '*and what about this?*' He leaves an open space for patient H4 to answer without jumping into the silence. In a recent presentation at the Wellcome Trust, Prof Zakrzewska, asserted all too often clinicians jump in, the average time before they come in while a patient is speaking being 23 seconds (Zakrzewska 2012, Marvel et al 1999). These open questions elicit valuable and detailed information. For example when patient H4 says '*it is needles*', clinician H attempts to clarify, '*it is needles for you, so it is telling me about the stabbing nature of your pain*'. Patient H4 - 'yes'.

To card no 5, (fig 88c ) Clinician H leads with another open question '*and what about this?*' Patient H4 again demonstrates with his hand on his face, saying '*that is the burning sensation and that will bring the tears and the weeping from the eye*.' It is a more emotive response than any I saw elicited in consultant H's baseline consultations. At 6'57" in there is another example of clinician H checking he has understood what the patient is trying to communicate, '*so the electric sparks flying off, is that what you are telling me, is that what you are getting at?*' Patient H4 nods, 'yes'. At 7'18" Instead of assuming they understand each other, both speakers return to the images to check. Frequently the clinician referred to the patient's interpretation of the image using the images again and again as a shared reference point. The descriptions become jointly constructed, led by patient H4's response to the images.

## Images revealing emotion

Patient H4 becomes very emotional when he looks at PAIN CARD 28, fig 88e (one of the most frequently selected images). He describes how it is like when he was weeping and his eye was red at which point he touches his face emotionally. There is a strong sense of the intensity of it and of emotion. His wife joins in making it clear they have discussed the images together in the waiting room, saying *'didn't you think that might also be when you are embarrassed'*.

Patient H4 stops looking at the cards and sits up straight looking into middle space, hands apart as though his head were between them, saying *'yes it could be'*. In this way the card initiates the patient bringing this emotion directly into the room, in the present, saying *'I could be having a conversation with you just like this and then all of a sudden it starts with no warning'*. The clinician listens. Instead of ignoring what are clearly emotional indicators, he picks up on what PH4's wife has said about embarrassment, *'it is interesting you say about embarrassment'* moving his own hand over the card rather than looking at the patient. Again, unlike the closed questions of the baseline consultations he asks *'tell me a bit more about that'*. The patient opens up at this, describing his embarrassment and the twisting nature of his pain, as he uses a handkerchief to cover his face. The clinician insightfully asks: *'when you don't have pain do you still get feelings of embarrassment?'*

## Cards eliciting new and detailed information:

At 8.06 in, the clinician, holding up one of the cards again gives the floor to his patient *'what does this say?'* PH4 answers describing his need to hold his head to ease the pain. Other cards also elicit detailed information, for example card no 9, fig 88f, (another one of those most frequently selected). Patient H4 uses this to explain the dragging feeling he gets. His wife tries to return to one of the other cards, pointing to its space on the corner of the table. The clinician at this point asserts his authority over the consultation, overriding her and continuing to discuss issues of mobility and PH4's shaking which had been raised by the cards earlier. He returns to her question later. It has become a richly woven



negotiated discussion, the patient's wife contributing to the description of how excruciating the pain is. The corner of the table and the area between is active, all speakers entering it. By 10.07 all their legs are fairly entwined, and the negotiated exchange has revealed much information relating to emotional components and impact. At 41.37 the disturbed nature of his dreams is discussed as well as new information about: the fact that he shakes; the nature of his pain sensation and his feelings of embarrassment affecting his social activity. There follows very precise in-depth questioning from clinician H about the physical manifestations of pain, sensation, visual disturbances, numbness tingling etc. At 17.06 in the clinician returns to the cards, this time the one of electric sparks, card 5, fig 88c, asking *'does it feel like this?'* PH4 affirms it does, producing the card referencing the needles and his sharp pain. The clinician has been using the cards both as triggers and as shared reference points. At this point clinician and patient are jointly constructing a pain narrative.

### **Cards impacting on dialogue dynamic: increase in rapport**

At 20'29" in when the cards are no longer being used and the clinician has reverted to more standard questioning, he asks about triggers to pain; directly referencing a conversation they had had earlier while using the cards: *'You have already told me from the cards that you don't like touching your face, and shaving, but ... what else triggers the pain, can you give me examples such as talking, drinking, eating?'* Patient H4 adds that the pain is also triggered by cold wind blowing in his face.

Clinician H is using information gleaned from the cards to elicit further narrative later in the consultation. This demonstrates to the patient that he has listened; helps build rapport and increases trust as well as generating detailed extended descriptions of the specificities of PH4's pain and the contexts in which it occurs. There follows a series of precise questions about the nature and type of pain, Clinician H again references something which arose earlier using the cards at 24.57 in when he asks *'tell me about the shakes – when did they start?'* PH4's wife explains he has had them for 30 years but they haven't mentioned them to his GP! This is valuable information in terms of his overall care, and appears not to have been discussed with any previous medical professional despite being ongoing for three decades. It is impossible to argue that it only came to light

because of the cards, but it is highly suggestive that the type of discussion which was able to happen as a result of using the cards, elicited new information such as around his 'shakes' which may otherwise have remained concealed.

I have described this part of the consultation in considerable detail because it is this detail which evidences the specific ways in which the images are provoking more negotiated and equal exchanges and fuller and richer descriptions. It is also spectacularly different from the interaction pattern of clinician H's earlier baseline consultations. At 43' PH4's wife admits that at one point they were worried that H wasn't the right doctor as it said facial pain on the letter but now they don't feel worried as clearly he is the right person to help them. They both assert that now they feel confident that this is right.

The clinician clarifies at 44', *'we have the diagnosis'*. He then suggests a very practical management plan telling them to call sooner rather than later if they want advice or have queries. Following on from the discussion about his shakes Clinician H affirms he will ask for PH4 to be seen in the falls clinic locally to discuss his shakes and mobility issues. The cards have clearly not driven the consultation away from medical issues, they have been integrated into a medical consultation and have elicited extra information on which the clinician is acting in terms of future management.

This finding is supported by Clinician H's own comments in the post-consultation questionnaires: *'usefully allowed focus on different aspect (mobility matters)'* and *'Helped patient relate his pain experience'*(CH4). In his post consultation questionnaire responding to his other study consultation using images, (CH3), Clinician H also observed: *'I think it helps patients describe their experience of pain. They often complain that they are not able to get clinicians to understand the impact of pain on them - Photography might help them relay this better.'* From a man whose use of verbal language is very precise and who had been sceptical of any additional value the images might provide, this is generous and striking. It supports the premise that the images are able to effect change in the texture and dynamic of pain dialogue in the clinic.

### **Clinician A:**

In contrast to clinician H, clinician A has a strong belief in the value of patient narrative and the potential value of images to consultation dialogue. There were still significant differences in her consultations using images; her study consultations showing a 7% increase in satisfaction from her baseline consultations.

In baseline consultation (without images) PA1 the role of speaker was vied for and control of the dialogue contested. Generally each speaker's utterance refers back or forwards to their own statements rather than responding to the other. It is possible to visualise this particular patterning through a linkograph created out of a short section of transcript: 61'58" – 64'29" in. Linkography is a technique introduced by Goldschmidt (1990, 1992, 1995) to analyse designer's cognitive activities and the structures underlying them. It analyses links in idea development documenting steps that look backwards linking to preceding ideas and steps looking forward, linking towards subsequent ones. The design process can then be examined in terms of patterns that display the structural design reasoning (Gero and Lindemann 2005). The same can be done with speech looking for patterns within the dialogue, by linking utterances to preceding utterances by the same or another speaker and/or to following utterances, identifying where these initiate an idea or respond to one already voiced.

From the patterning visible in fig 91, the conclusion can be drawn that there was little response to each other, each speaker being preoccupied with trying to get their own beliefs across, rather than responding to what the other said, allowing few opportunities for interaction; a dynamic which intensified with the widening gap in agendas as the consultation proceeded.<sup>13</sup>

In contrast a linkograph created from a short section of transcript from the study round, (CA3, 31'38" in) reveals a richer more integrated pattern, with speakers responding to each other's utterances and ideas. See fig 92. There is an obvious confounding factor, that the patient is different, and different patients evoke different responses in clinicians. However it demonstrates that viewing and handling the cards has a tangible effect on the patterning of dialogue and interaction which could be carried over into the remainder of the consultation.

Clinician A prompts PA3 to use the cards at the beginning of this extract: '*You might want to use the pictures if that helps*'. A more open and interwoven dialogue evolves. The extract is purposefully taken from a period where the images are being handled, in order to make a concrete comparison with the baseline exchange above, (CA1), where they were not. As the aim of this analysis is not to suggest images as an alternative to verbal language or traditional measures, but to examine how and when they impact on these, there is a validity in selecting extracts on which they have an observable impact - in the full knowledge this will not always be the case.

Handling the cards draws clinician and patient closer together physically but also into a shared exchange. This dynamic is repeated when clinician A goes through the McGill questionnaire and the patient leans forward to look at it on the table. As has been noted with other patients, PA3 says '*no*' to most of the more complex words from the McGill. The McGill words seem generic in comparison with the patient's own language generated in response to the images, such as '*I called it my face ache*'. There is not room for this personalising of language within the McGill.

The performative nature of their roles is apparent. The patient is open, with a physically open stance, but vulnerable in some ways, allowing herself to be slightly exposed, but also self-possessed, taking time to answer questions. Professional status is conferred on the clinician who is willing to take on responsibility for guiding and directing the consultation. Her performed role is boundaried, coming across as safe, responsible, clear, empathic while retaining professional boundaries. This is in striking contrast to her role in Consultation A1 where conflicting agendas rendered the space between patient and clinician a battleground more than a place for respectful exchange and PA1 had managed to anger her. Clinician CA3 listens carefully responding to her patient's replies and when there is a long pause from the patient she waits for her to finish her sentence or find the words rather than jumping in. Silence is difficult to maintain but provides time for patients to think and reflect. If the clinician can hold eye contact and be ready when the patient '*comes back*' it can be extremely valuable. This was a mutually respectful exchange with a lot of listening space on both sides, reflected in the patterning of the linkograph. When reading through the transcript without the video-tape however, it appears as though clinician A cuts off PC3 before she has answered. The video-recording show this is not the case, highlighting the nuanced nature of the

human voice and human exchanges, reinforcing the value of relying not only on transcripts and/or evaluation forms but witnessing and examining the primary recorded material.

Unlike in baseline interview A1, where both patient and clinician get so caught up in trying to put across their own perspective they lose sight of the gear changes, in this study consultation, clinician A3 immediately notes when there is an emotional gear change triggered by one of the cards.

There is a very long pause at 21'10" where clinician A asks the patient if she is anxious or depressed. PA3 finally answers '*I am an anxious person*', and after another long pause: '*it worries me*'. She puts the remaining cards she has been holding during this conversation on the table when she goes for physical examination. They are still there when she returns.

Clinician A prompts her at 31'38" with another chance to talk about the images which were laid face down on the table. '*Is this about your work?*' (see fig 93). PA3 says '*no, its about hospitals, and anaesthetics, ... I am frightened of anaesthetics.*' This is a critical point in the exchange revealing information not previously gleaned. Without the card as a visual stimulus it might never have been revealed before the end of the consultation. PA3's fear of hospitals and anaesthetics might well have impacted on the intensity and recurrence of her facial pain and related to her previous experience of cancer:

*'For me it's a toss-up do you ignore things like this, thinking, ah it's nothing, or do you go and ask about it, because you're frightened of ignoring something?'*

At the very least the conversation that ensued directed the clinician towards her fear in relation to surgery, and her fear of her face pain being the cancer returning. This may have been a negotiated consultation without images, but it would be difficult to deny that the images elicited more information and a richer and more detailed language.

The final two extracts I would like to examine are taken from clinician D and K's study consultations (using images). Both are likely to elicit emotional narrative as their fields are psychology and homeopathy. However the images still appear to trigger significant change in language and interaction. With these two clinicians I have compared not the baseline and study consultations, but

sections from the same study consultation before and after the image cards were used. This way the variability of patient personality can be eliminated.

### **Clinician K**

Patient PK3 enters and puts all the cards she has selected on the corner of the table. The space between patient and clinician is animated, both entering into it, frequently mirroring each other's stance, (eg 13'15" in). The patient speaks a lot, as the clinician gently probes her, but when the cards are not being directly addressed, it appears to cycle rather than going in any one direction. The cards provided focus. The roles of speaker and listener are shared relatively equally between them

The cards revealed a pivotal issue – PK3's relationship with her family. At 26'25" Clinician K asks '*do you see your children?*' to which PK3 replies, '*I give up on them*'. Clues emerge which are expanded on later through reference to the cards. The clinician listens intensely to what the patient brings, while trying to relay the fact that mood influences pain.

CK3: '*There is no absolute treatment for it, we know at the moment, but in your case the mood and anxiety might be affecting it. The mood plays a big role ... what do you do about your depression?*'

PK3: '*nothing*'. (48'52")

CK3: '*Do you see your children regularly*'

PK3: '*yes, they are ok.*'

This last is of note in relation to counter information gathered when the images are used. At 55.31 the clinician picks up cards again and returns to asking PK3 about them. The space between speakers becomes increasingly active as they pour over the cards, moving them around on the desk together. PK3 describes her response to some of them, for example '*sharp like a knife inside*'. The cards elicit precise descriptions of the quality of the pain, a less cyclic conversation. Then she confesses, '*I can't take it no more*'.

The cards act like triggers as she finds her way through them laying them out in front of her. Additional information is elicited during the process, for example, she has to take her '*dentures out*' regularly, and she has very cold hands and feet, so cold that when waking in the morning she has to put on her gloves. Looking at the image of the medications she says '*tablets, I hate them.*' (57' 56") asserting, '*I don't want them, nothing to do with it*'. Medication is once again revealed as a contested issue.

Viewing image card 15, that of a broken chain, (see fig 94) PK3's statements conflict directly with earlier statements that her family 'is ok'. '*I feel loss*'. From this point on she talks about her sense of loss, continuing at 58' 06" '*That is a gap,*' looking at the image of the chain.'*I feel the gap for me*'. She becomes very tearful, continuing at 58' 30":

*I feel a gap ... THEY HAVEN'T GOT NO TIME FOR ME – CHRISTMAS  
ALL OF THEM IS NOT GOING TO COME*

She starts crying, leaning on the desk. This appears to be a critical point in the consultation, triggered by one image. CK3 responds: '*I am sure we can help to understand this a little better*'. Nodding PK3 responds, '*you know I give up on medicine*'. The cards reveal an intensity to her sadness, the painfulness of the gap she feels between herself and her family. In the context of her earlier assertion that she gets on ok with her children, it represents a significant increase in relevant information, as well as evidencing the trust she has developed in this clinician, borne out in her evaluation form answers.

I am not arguing that it is necessarily good for a patient to be reduced to tears during a consultation, though it often happens, but what I am arguing is that the information which prompted the tears - that she didn't see her family enough and that she experiences this as intense loss, - has direct relevance to her pain experience and the way it might be managed. A form of denial may have existed and the images prompted PK3 to recognise her real feelings and concerns. Had this information not been elicited the consultation could have concluded with an acceptance of her earlier statement, omitting vital information.

CK3: '*Do you see your children regularly*'

PK3: '*yes, they are ok*'.

## Clinician D

Clinician D's consultations, as a psychologist, elicit emotional and social context whether images are used or not, however, the images still prompted observable changes in language and dynamic.

Many of the patients focus on loss when reviewing the image cards, raising it as a central issue. Patient PD4 is no exception, selecting image 49, fig 83, depicting the word 'loss' and using it to describe pain as a 'blank'.<sup>14</sup> What is unusual about PD4 is he claims to have no visual image for pain. Being prompted to discuss loss through reference to the cards may have made recognisable that which had been previously unrecognisable or 'lost', helping its transformation into something new, which could be 'found'. It is a process of recognition of that which is neither tangible nor visible, that the images appear to initiate.

In consultation D3, the changes the images effect in body language and use of space are particularly noticeable. In this consultation there was a measured, relatively calm and clear dialogue. The only time the language became more emotive was when using the cards, the images acting as a gear change, the mood and intensity increasing from their use onwards. Clinician CD3 gives an impression of endless time as she faces PD3, but the space between them at the beginning is wide, not crossed by hands or legs. Both maintain their own third of the frame, neither moving into the middle third. The material being discussed is distressing from the start, but there is a sense of each speaker having a distance, of being self-contained in their own physical and metaphoric spaces. The first time the corner of the desk is used is at 14' 29", when CD3 places medication letters on the table between them, but no other activity happens within the space until 25' 13" when PD3 places his glasses there. He puts his hands out to show they are shaking a little. PD3 says: *'the surgeon told me I have suffered a stroke... all these things ... what is causing it? It's such a shame I don't have the picture, if I put a picture of how I look now, you can see the difference'*. A desire for visible evidence as proof is raised, the well-documented need to be believed that this project aims to address.

The pattern of dialogue is equally spaced, with little interruption to either speaker, they give each other linguistic as well as physical space. Clinician D makes many affirmative nodding sounds demonstrating she is listening. After a



distressing history, just before they pick up the cards, at 35'17" patient PD3 moves his feet towards the clinician into the space between them and by 38'40" clinician and patient are mirroring each other's positions – hand to face. PD3 like so many patients states, *'I just want an answer – I don't know what happened'*. At this point, 39' 40", CD3 asks *'Do any of these pictures make sense of it?'* PD3 replies 'yes'.

They begin to reference and handle the images, this is the first time clinician and patient move into each other's third of the frame or actively inhabit the space between them. Now the corner of the desk becomes animated as the clinician spreads the cards out over the desk. PD3 moves his glasses to clear space for them, taking a couple which he puts side by side, creating a new narrative. He takes control of the way the cards read and thus the narrative they construct. As with clinician H's consultation, the images have become physical translations of pain. They prompt the patient to involve his body, to bring the physicality of pain, its corporeal location into the room, while discussing its emotional framing.

At 41' 07", responding to the images PD3 describes his pain as *'like an electric current – it moves around'* showing it on his body with his hands, demonstrating how he pinches himself to fight the pain and how it moves on to another bit of the body, so he pinches himself there. This is a very graphic, emotive, personalised and physicalised description where his own body becomes an additional canvas. *'I pinch, and pinch and pinch'* <sup>15</sup>

Returning to the cards PD3 explains, *'that bit of the picture looks like being human but the other doesn't, the other side of the card is because I don't know myself anymore – it is not my body.'* This feels pivotal, new information is revealed triggered by the cards. PD3 describes how he has become disconnected from his sense of self, the extent of confusion and separation he feels from who he used to be. A clear, personal description follows, less spiralling and more focused as he continues showing the pain with his hands running all over his body, a marked contrast to before the cards were being used when both speakers were completely still. *'Initially it tingles and then it went away and now it is just numb'*. CD3 returns to asking him about feelings of not being him self. The cards have brought his body into the dialogue in a very material way. CD3 moves position and there is something more fluid in their body patterning and consultation dynamic.

More information is revealed as PD3 continues to look through the cards. At 47' 33" he touches them describing his '*stabbing pains*' and saying he wears a tight belt to relieve pain, '*I tried to move away from being on my own in a room locked up*'. New information tumbles out, at 49' 27" '*I really like really really scary stuff to read ... I find it hard to climb stairs , I would like to be able to climb stairs again. ... I want to do it but my body doesn't allow it. ... I am a very vibrant person, but the person I am now, I don't know that person*'. At 55' 56" PD3 affirms '*pain is evil*'. He describes the pain as '*digging*', demonstrating with his hands digging against the side of the desk. This links back to the medieval association of pain with punishment and evil, evident still in so many contemporary patients' testimonies. The footage is compelling as the hands dig into the corner of the table in an evocative movement , building up to PD3 moving his stick into the space between him and Clinician D and starting to get up and move around, eventually moving out of frame, describing how he needs to walk around and to move.

The language has become richer, more vivid, more detailed and the body has become integrated into it in a graphic manner, reminding us that, wherever it is processed, pain is experienced through the body. The body is not a 'blank slate awaiting inscription' it is an active agent through which we mediate the world and experience sensation. It is through the body that the self is '*constituted in ways which are not exhausted by discursive articulation*' (Lennon et al 2013 p 3). The body, particularly when in pain, is central to the consulting room.

It is difficult to imagine that these emotions and parallel physical and verbal evocation of pain would have been elicited from selecting a number on a scale from 1 to 10. This depth and breadth of distress requires a far fuller discussion. Inevitably he would have had this with clinician D with or without images, but it does appear that, as in other consultations, the images have triggered an emotive, graphic and individual language, promoting changes of patterning in the body as much as the verbal language. A full analysis of all the consultations needs to be carried out to ascertain how often these observations are repeated elsewhere, and can therefore be generalised. What is apparent is that it is worth doing and has potential to reveal valuable information about the patterns of consultation dialogue and the beneficial effects of inserting images into them. What is equally apparent is the value of examining the space between us as a membrane for two-way exchange.



Fig. 9

# CONCLUSION

## Pain treatment as a 'human right': grasping the moment

*Greater scientific knowledge has triggered a change in social attitude that in turn has brought pain prevention and pain treatment to the forefront of our awareness. Indeed, several professional organizations around the world are campaigning for recognition of pain treatment as a fundamental human right. (Cervero 2012 p xiii).*

We need to grasp this moment: when the pain pathway is being developed in the NHS, more pain management is being introduced into medical training, the IASP has declared 2014 the year of facial pain and organisations around the world are, as Cervero affirms, campaigning for pain treatment to be regarded as a '*fundamental human right*.' Building on this momentum, I believe it is imperative that we integrate the best research and specialist expertise from all disciplines which, together, can help us understand the complexities of chronic pain; from the exciting scientific research being carried out at a neuronal level, the understanding of behaviour and society the psychologists bring, to the arts and humanities which help us see and understand ourselves - our relation to our bodies, and the role our individual and collective narratives play in the framing of pain and suffering. In his introduction to the Medical Humanities Association Conference in Truro (2010) Professor Alan Bleakley stated that : '*As a science using practice that is both humane and employs artistry, medicine is the discipline that best questions a strict arts and science divide*.' I believe it is a moment to integrate the best of scientific and artistic practice in order to find ways of managing pain for the 21<sup>st</sup> century and beyond.

This thesis and related projects has attempted to begin such a journey. In it I have been hugely helped by Professor Joanna Zakrzewska, without whose insights and commitment the value of the work would have been very limited, and by members of her clinical team who have agreed to pilot the PAIN CARDS and the creative and generous pain sufferers who worked with us. The process has reinforced my belief that any artist undertaking this type of project needs the

full backing of clinical professionals, as well as their institutions, and if working with vulnerable adults, access to experienced psychological supervision during its course - for me generously and sensitively provided by Dr Amanda Williams. I have also benefited from being situated in a stimulating and thriving community of artists and students, in particular my practice supervisor Dryden Goodwin whose creativity and skill has helped me develop as an artist, and from the expert and astute guidance of my primary supervisor Dr Sharon Morris. It is the weaving of threads offered by all of these participants which has made it a journey worth undertaking and underpinned and validated the discovery of new knowledge within it.

The data gathered during **face2face** and analysed in chapter three is unique. It provides an enormous wealth of material about doctor-patient relationships in the setting of chronic pain. At a future date, using the expertise of professionals from other disciplines, from within and beyond medicine it will provide insight into the role of the humanities in pain consultations which has never been attempted before. The guiding principle throughout the **face2face** project has been *negotiation* and the value of *good communication*. These will remain the basis for all work going forward.

### **Aims and conclusions of the thesis**

The overall aim of this thesis was to research the impact of photographic images and image-making processes on doctor-patient pain dialogue and on mutual understanding and rapport in chronic pain consultations. It attempted to understand the mechanisms by which aesthetic spaces and visual metaphors can influence language around pain, promote more democratised doctor-patient communication, and ultimately improve healing. It hypothesised that a visual language could provide an alternative means for effectively communicating pain, asking whether a series of photographic images of pain co-created with pain patients, could provide an alternative language for pain. It included an examination of the intersection of visual and verbal language and the ability of images to re-invent and reinvigorate both, framing language not as a neutral objective vehicle but as an active process bringing new worlds into being. The thesis concludes that it is not so much the visual language on its own, but its

intersection with verbal language and the relational influence of the images as objects or PAIN CARDS which has impacted significantly on the pain consultations studied.

The PAIN CARDS are not offered as an alternative to existing practices or measures, but as a tool which can complement and enhance them, where appropriate. Where patients and clinicians respond to the cards, they appear to effect change in the texture of the dialogue, the richness of the language and facilitate more collaborative and equally balanced exchanges, including the elicitation of new significant information. The overwhelming difference the cards made to the dialogue is in the detail and depth of description of both physiological and psychological suffering, evident in both clinician and patient language. Detailed discussion of emotional experience, absent from many of the base-line consultations emerges in the study consultations using images. Issues of power, manipulation and styles of discourse, such as changes from interrogative to conversational style emerge as key themes, along with observable changes in rapport demonstrated through body language and use of space. Whereas in most of the baseline consultations the physical space between patient and clinician remains passive and empty, in the study group, both clinician and patient frequently inhabit and animate it, resulting in an inter-weaving of limbs which spills over into a more equally woven dialogue. The performed nature of clinician and patient roles is apparent and the language of the clinic as much as the space itself emerges as contested, making visible the power struggles enacted within it. The patterning of roles of speaker and listener, and attempts to vie for control of the role of speaker appear mediated via the images. Instead of driving the consultation away from medical issues, as some clinicians feared they might, they have been integrated well into the medical consultations uncovering extra information with direct bearing on future management. This finding is supported by clinicians' own comments:

*usefully allowed focus on different aspect (mobility matters) and helped patient relate his pain experience (Clinician H)*

*Enabled a holistic person centred consultation (Clinician A)*

It is tempting to conclude that without the cards the level of suffering revealed in the recorded consultations studied might never have been exposed. It is impossible to know whether this is the case or not, but what can be observed is

that the ability of the cards to trigger discussion of the emotional impact and components of pain is evident from both the recordings and the corresponding patient and clinician questionnaires. This supports the hypothesis that images can and do elicit significant narrative which needs to be heard, witnessed and discussed within the consulting room.

The growing evidence for the influence of mood and emotion on pain experience and pain intensity has been discussed in previous chapters<sup>1</sup> (Tracey 2005, 2007, Wiech et al 2009, Charon 2005, Gundel & Tolle 2005, Eisenberger et al 2003) . This emotional narrative therefore has a direct and integral effect on the intensity of an individual's person's pain and its future trajectory and if images can elicit this early on in the consultation they are likely to improve outcomes and save time in the future.

The hope is that by encouraging the patient to lead the dialogue using the images as stimuli they will be encouraged to use language from their own worlds, catalysing new words, and a more negotiated dialogue. I believe an aesthetic space, as provided by these photographs, can expand dialogue rather than reducing it to its well-worn habitual patterns. The images can be seen as generative of language rather than as an alternative to language.

I am aware there is a real lack of time in a target driven NHS culture and clinicians may feel there is not enough time to use the cards. However I would argue that in certain circumstances time can be saved through using the images to discover the issues patients want to discuss more quickly.<sup>2</sup> Time would be well spent using the images early on if a rapport is improved and management programmes, which patients are happy to adhere to, achieved earlier than usual. This belief is echoed by clinician H who, despite being sceptical at first, told me he thought images might speed up identification of what it is the patient feels they need to talk about. Clinician A also told me about a man she had seen with trauma-induced pain who had been correctly diagnosed by three consultants but at the end of her consultation, said this was the first time anyone had explained his pain to him thoroughly and he now felt better able to cope. Time well used, saves time later, and the target driven NHS culture is doing pain patients few favours.

## **Reaching towards tolerance of ambiguity and uncertainty**

Photographic images allow ambiguity and uncertainty. What I feel would benefit medical pain dialogue is a similar toleration of ambiguity. Pain specialist Charles Pither, is one doctor calling for such toleration of uncertainty:

*We have to live with uncertainty. If, as has been suggested, only 15% of our patient have a clear-cut pathology, (and I mean real certainty, not conviction) then what do we do with the remainder? Order another test? Refer them back for more work up? No, we have to move forward living with that uncertainty, and half of our task is to convey that to our patients, so that they can do the same. (Pither 2011 p21).*

## **Towards an equal mutually beneficial exchange**

It is not just the length of the consultation that matters but the quality of the exchange enacted within it. Through writing this thesis, the value of both the photographic portrait encounter and the clinical encounter being opened up to a shared gaze and to a collaborative dialogue has become ever more evident. I would argue for the benefits of a collaborative practice with pain sufferers being included within a fine art framework allowing the visual work produced to resonate with those outside the collaboration and to have meaning in both medical and gallery contexts. I would agree with Professor Alan Bleakly and his colleagues (Marshall & Bleakley 2013, Bleakley 2006, Bleakley et al 2011) that a less hierarchical and more democratized dialogue in the clinical setting and in clinical training would benefit patients, medical students and clinicians, and argue that visual images are one means of effecting this. Kenny's study of doctor-patient interactions supports the need for less paternalistic and hierarchical relations within medicine and the conclusion that ultimately better communication reduces suffering and not only saves time, but money:

*A recent special issue of the British Medical Journal was devoted to the doctor–patient relationship and the needed transition from paternalistic medical care to partnerships between doctors and patients. In one of the articles, Berwick argued that “. . . when patients become co-equal with*



*health care providers in controlling care, making decisions, and treating themselves with coaching, outcomes improve, costs fall, satisfaction rises, and even physiological measures look better (Kenny 2004)*

Bleakley and colleagues argue that:

*The medical humanities may be reformulated as process and perspective, rather than content, where the curriculum is viewed as an aesthetic text and learning as aesthetic and ethical identity formation. This article suggests that a "humanities" perspective may be inherent to the life sciences required for study of medicine. The medical humanities emerge as a revelation of value inherent to an aesthetic medicine taught and learned imaginatively. (Bleakley et al. 2006 p 197).*

That one of the greatest causes of medical error is poor communication (Marshall & Bleakley 2013), that poor communication is one of the main contributors to inadequate treatment of pain (Kimberlin et al. 2004, Yates et al. 2002) and that communication at present is the sole route of diagnosis of chronic pain (Zakrzewska 2013), provide a solid argument for paying great attention in the future to the language, narratives and relationships constructed in the consulting room. With 34% of the British Public identified as suffering from chronic pain by a government survey for the NHS and an ageing population, this is not something we can afford to ignore. However, rather than addressing short term targets aimed at reducing welfare, would it be more cost effective to explore the benefit system as offering opportunities for re-training, flexible working, and supporting creative approaches to work and productivity, rather than the punitive system people with pain currently face where medical examinations appear set up to evidence their ability to work, even though that work may itself have been part of the problem? How pain manifests itself within the structures of society is not divorced from the intellectual enquiry or creative output around it, both of which can shed light on what it puts at stake for us individually and/or collectively.

## **Limitations of the *face2face* project**

The numbers are relatively small for any quantitative study, so no vast claims can be made from the statistics alone. However, taken alongside the qualitative data, they highlight interesting features and key findings in the material, identifying phenomena requiring further exploration and suggesting new research questions for future studies. Thus they support and inform the qualitative data gathered.

As it needed to be the first encounter between patient and clinician in the recorded consultations there were inevitably confounding variables, in particular the different personalities and conditions of patients. (The clinicians were the same in both rounds. However as the study group happened a year after the base line group, factors could have arisen in the intervening period which influenced the way the clinician consulted. Also to a large extent clinicians were self-selecting and no record was kept of the number of clinicians approached and the number who agreed to take part.)

There was patient self-selection but no selection by the researches, reducing the likelihood of bias. There was no selection of which patients participated in round one or round two - it was purely dependent on what date they were on the waiting list, ie during years one or two. Therefore there was no bias in the selection of participating patients, and there should have been no significant difference between base-line and study cohorts, although both groups only included patients who agreed to have their consultation recorded - which may have excluded some groups. Every attempt was made to keep all other variables constant within both baseline and study groups, such as method of contacting patients, consulting room and waiting room, and arrangement of furniture within the room. The fact that there was a base-line round for each clinician evidences the importance we placed on having a control. As the image resource is not offered as an alternative to current treatment options, but as an additional tool or complement, it also, in my view, does not necessitate randomised or double blind trials, which would be impossible to carry out anyway. The randomness we achieved was through the selection of patients in that every patient on the waiting list for each clinician participating was sent the

same invitation to participate and same information sheets. The first two to volunteer from each waiting list were accepted onto the study. We did not keep records of the number of patients who were approached and refused to participate, which I recognise is a limitation and is something we would address in future. We did however end up with a wide range of age groups and ethnicities relatively evenly spread across both genders and a wide range of clinician specialties - from surgery to homeopathy.

The images included in the pack of PAIN CARDS went through a rigorous selection process, discussed in chapter three, which did not aim in anyway to be randomised or objective, being part of an artist's practice and part of collaborative co-creative processes evolved through close dialogue with those living with pain. The final selection was the result of considerable discussion with both patients and clinicians, supported by data evidencing which images had been selected most frequently in the past (for example from *perceptions of pain* and from earlier focus groups) and which images had been picked up on by other pain sufferers from within the new images in *face2face*. I drew up a long list of images in response to the factors above, and from discussions with patients and took this to Professor Zakrzewska and her clinical colleagues to identify which images they felt were most relevant to conditions they see regularly in their clinics. From this the short list of 54 images was drawn up. It is unclear whether or not this is the optimum number or optimum size for the cards. These will be further evaluated in future patient focus groups and in consultation with Professor Zakrzewska's pain management teams as well as during the on-going development of the research with an expanded interdisciplinary team in the future.

Bias would necessarily have been introduced into the patient journeys as the patients had to commit to spending a considerable amount of time co-creating the images with me, including during periods of severe pain episodes. The participants who volunteered to co-create images of their pain came from a wide variety of backgrounds but it is observable that several (though not all) had experience of artistic practice, such as textiles, interior design and music and so the participating patients in that particular strand of the project may not be representative of all pain sufferers.

## **Limitations of the thesis**

Because of the restrictions imposed by the word limit, alongside the large amount of data generated by the project for inclusion, discussions on topics such as power-dynamics and democratisation of language have necessarily omitted in-depth analysis of key figures, who have been employed more to support the central hypothesis than as subjects for analysis in their own right. So much has been written on Foucault for example, that with a tight word count, I did not feel there was much of significance I could add to existing debate. I have not therefore entered into any rigorous discussion of the different kinds of power Foucault identifies, nor the emergence of productive rather than reproductive power, nor made reference to the distinction between the capillary power Foucault would have identified as belonging to the patient and the doctor's exercise of what he would term sovereign power in a consulting room context. I have indicated the relevance of his seminal work on power to the research but have not examined it in depth within the thesis, although it would probably strengthen research papers arising out of this material to do so.

There are also many occasions where other writers could have been mentioned, for example Bachelard and Bakhtin, whose works examine, respectively, the poetics of space and the value of dialogical communication (Bachelard 1958 and Bakhtin 1986). Again although they are key figures in any discussion of the consulting space, as an intimate space of utterances, I had to prioritise and limit the number of theoretical approaches to the material I was able to make within the word limit and thesis format. They are important figures to consider in future publications, and their inclusion will deepen my understanding of the communication process and subsequent discussion of the need for democratisation and balancing of power relations within medical dialogue. Prof Alan Bleakley writes knowledgeably and convincingly (Bleakley 2010, Bleakley et al 2011, Bleakley and Marshall 2012) on the feminisation of the medical gaze as part of the current democratisation of medical dialogue, but although an interesting and valuable framing of the phenomenon, I have chosen not to reflect the gaze or the democratising process as gendered but to focus more on the challenges and benefits of crossing and navigating spaces between different perspectives, irrespective of gender. It is the attempt to shift perspectives

between speakers, to encourage a dance of dialogue, a duet rather than solo performances, and to stimulate fluidity within communication which is the focus of my own interest and I have chosen to frame the aesthetic space, rather than any particular gender, as effecting it. However for an interesting discussion of pain as gendered (feminine) and its treatment as contrastingly gendered (masculine), please see Bleakley et al 2011. The more the research develops the more the central research questions appear focused around whether images can improve the quality of communication between patient and clinician and what improving the quality might mean - how it might be measured. It may be well worth re-visiting the literature around narratives of power in relation to doctor-patient communication in order to understand how a democratisation, if it is happening in response to the images, is manifesting itself, and why.

Although much has been made of the polysemy of photographic images, I realise that some of the dominating metaphors, namely the shadow, have been allocated purely negative rather than a variety of interpretations which could include positive ones. In future I would like to delve into some of these metaphors, particularly the shadow in much greater detail, adding observations drawn from psychoanalytic theory and a wider reading of the symbolism of the shadow, considering as well Fox Talbot's use of 'shadowgraphy' (photograms) as a way of re-linking the content of the images to their processes and origins of photography. Helen Sear for example frames the shadows within her own photographs as positive symbols, an interpretation which hadn't occurred to me, while St Peter is frequently represented as healing the sick with the shadow in many fifteenth century frescoes. Acknowledging alternative readings would help me recognise the ways in which my own reading is situated from within the context of my own history of pain, and relationship to it, influencing not only the creative process behind the images, but the interpretations ascribed to them.

At this stage it could never be an exhaustive analysis of the material gathered during the **face2face** project. What I hope my brief analysis has done is to raise questions and hypotheses which a multi-disciplinary team might take forward in the future, to help us understand the relationship between and generative impact on each other of images and words. It also evidences ways in which this image tool could be used in the future to improve doctor-patient communication.

## **What can art offer medicine?**

Two final questions are what can art tangibly offer medicine, and where can this work go in the future? The thesis has attempted to explore and make clear the many ways in which the aesthetic space, its material form, its tolerance of ambiguity and polysemy, its multidimensionality and emphasis on process and collaboration can enhance communication and understanding of pain, and improve doctor-patient relations. It has articulated the reasons for photography and lens-based practices being an ideal medium for this enterprise, the sense of control that control of the lens confers, and authenticity it ascribes to subjective experience. It has attempted to understand the mechanism by which the photographs produce affect and effects dialogue through relational, semiotic and metaphoric theory, placing an emphasis on the potential of the image, and series' of images produced at different points in the patient journey to be transformative.

## **The future: *Pain: Speaking the Threshold***

The current enthusiasm for exploring images as a means of eliciting and communicating pain experience (outlined in chapter one) evidences the need for but also the generative nature of this work and its potential benefits to pain patients in the future. ***Perceptions of pain*** remains the first study I know of in which photographs have been used within pain consultations to help in understanding the subjective experience of pain, with a view to improving doctor-patient communication. ***Face2face*** has continued to expand this original research and deepen our understanding of its original hypothesis, making a unique contribution to the field.

The photographs and films have been exhibited in a number of venues since the start of the project, including the Science Museum, the Wellcome Trust and King's College, and the research presented at a number of academic and public conferences and meetings including, Alberta Canada, the Wellcome Trust, London, the National Portrait Gallery and in Calcutta for the 100<sup>th</sup> Indian Science Association Congress, 2013. This has attracted specialists to the project from other disciplines, so that I am in the incredibly lucky position of having a team of

experts, including my current supervisors, all at the top of their field, willing to take the research into the future.

The next step is to bring together the insights and methods of these experts to enhance the preliminary analyses developed in my thesis. My aim in the future is to integrate these approaches into a multi-disciplinary piece of academic writing as well as to explore a means of reporting the results visually and creatively, so they can resonate beyond the academy in more lateral and polysemic ways.

We have been incredibly fortunate in gaining UCL CHIRP funding for a new project ***Pain: Speaking the Threshold***, in order to carry out a multidisciplinary analysis of this unique material generated and gathered during the ***face2face*** project allowing me to build on my doctoral research. This three-year fellowship provides a sustained period with which to collaborate with an exceptional multidisciplinary team and benefit from a rich cross-fertilisation of ideas, insights and methods, taking the work and creative practice in new directions. The team already includes a distinguished range of academics: Prof Joanna Bourke (History, Birkbeck), Dr Sahra Gibbon (Medical Anthropology, UCL), Helen Omand (Film maker and art-psychotherapist, Studio Upstairs), Professor Elena Semino (Linguistics, University of Lancaster), and Dr Amanda C de C Williams (Psychology, UCL) as well as my current supervisors Dr Sharon Morris (Fine Art and Creative Writing, Slade, UCL) and Prof Joanna Zakrzewska (Pain Medicine, UCLH) who will be the PI's on the new project.

***Pain: Speaking the Threshold*** will not only further validate the PAIN CARDS as a new communication tool for rolling out across the NHS in the UK, but provide an opportunity to pilot the PAIN CARDS with patients from diverse ethnicities in London as a comparative study to assess the benefits for their global use in the future. This will allow us to evaluate the hypothesis that a generic trans-historic, trans-cultural iconography for pain is developing.

**and finally ...**

The photograph I did not take in Prague has resulted in a series of photographs, (I hope) of real value to pain sufferers and those who treat them. I will never forget the man whose tears resisted capture, but whose image remains fixed in my mind. This work is dedicated to him and all those, like him, who have given so much to make it possible - and to all those who will seek expression for their pain in the future.

In the words of one of the participants, it would make it all worthwhile if the photographs we have created could be available:

*'on a regular basis for everyone in the NHS', (Study code PMM3)*

and in the future, for those beyond the UK.



*Pain, that unpurposed, matchless elemental  
Stronger than fear or grief, stranger than love*

(Robert Graves)



Fig. 95

# NOTES

## NOTES: INTRODUCTION

- 1 ***Perceptions of Pain*** was a collaboration between myself, Dr Charles Pither, Medical Director, INPUT Pain Unit, St Thomas' Hospital and INPUT pain patients on their residential programme in 2000-2001. The aim was to co-create with pain sufferers, photographic images which reflected their unique experience of pain. These photographs were used in a variety of ways including: in consultations with Dr Pither and patients' healthcare providers to trigger dialogue, exhibited in London hospitals and, supported by an Arts Council Touring grant, in a variety of museum, gallery and hospital venues around the country. The project also gave rise to a number of studies and publications including a feasibility study launched at the British Pain Society Annual Scientific Meeting in Manchester in 2004.
- 2 ***Painless*** was an antennae exhibition curated by the Science Museum in London. With artist Helen Omand I was brought in to work with a group of pain sufferers who were helping co-curate the exhibition. This involved running a series of 4 art workshops, facilitated by Lucinda Jarrett, which lead to the co-creation of a film with Helen Omand and the participant group aiming to reflect the response of the group to the themes and objects in the Painless exhibition, informed by their personal experience of pain. The film is entitled ***fragmented lines***, 2012.

## NOTES: CHAPTER 1

- 1 Pain's usefulness is evident in the consequence for those who have congenital insensitivity to pain (Indo et al 1996)
- 1b James Giordano reformulates *maldynia* as an illness '*of seemingly idiopathic, intractable, chronic pain and subjective suffering within bio-psychosocial contexts*' (Giordano 2011)
- 2 A form of clinical practice defined as '*medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness.*' (Charon 2006 p vii) For a full discussion of 'Narrative Medicine' see Rita Charon's '*Narrative Medicine, honouring the stories of illness*' (2006) where Charon explores the need for doctors to develop their ability to listen to and honour their patients narratives as much as their scientific expertise.
- 3 Medical terms such as 'manage' are interesting and it might be worth exploring how language and image not only reflect but construct notions of pain.
- 4 See page 202 for a discussion of what experiences and people on the margins can teach us.
- 5 One of the respondents to the ***perceptions of pain*** pilot study suggested images might sometimes '*distract from the medical focus*'. (Padfield et al 2010 p 147)
- 6 For example during the same ***perceptions of pain*** Pilot Study one of the clinicians reported in her feedback from that she had always thought her patient was angry. Using the images, made her realise it was sadness and not anger and that she should refer her for bereavement counselling before referring her to a pain management programme. (Padfield et al 2010 pp 146-147)

*'The images allowed the patient to express their sadness which I had previously construed as anger Clinician CFF4'*

- 7 Interestingly when I first started photographing pain I described it as both an investigation into the isolation of pain, but also perhaps the pain of isolation.
- 8 An accessible explanation of her research can be found in the *PainLess* Exhibition at the Science Museum (2012-13) and its associated material on the web. <http://painlessexhibition.wordpress.com/start-here/pain-in-the-brain>
- 9 The words were actually gathered from a very small sector of society as were taken from middle class people in a hospital catering for university populations who generated relatively elaborate words, not necessarily used by everyone, more by white middle class academic /semi academic groups. (Bourke Carluccio 2011 b)
- 10 For example the work of Prof Anthony Dickenson (UCL), an expert in neuropharmacology. The idea or process of descending systems or nerve projections from the brain having the ability to *selectively* modulate pain processing before it is transmitted to the brain. This work re-evidences the relationship between the brain and the modulating of pain experience.
- 11 However the majority seem to have focused on children
- 12 '*A Narrative based future for Healthcare*', Launch of the International Network of Narrative Medicine hosted by King's College London and co-sponsored by King's College London and Columbia University Medical Centre, taking place between 19 – 21<sup>st</sup> June 2013.  
<http://www.kcl.ac.uk/innovation/groups/chh/Narrative-Medicine-conference-/About-the-conference.aspx>
- 12b Originally it was two taster sessions followed by six workshops where clients worked in a therapeutic environment to explore visualisations of pain through paint, facilitated by Simon Jackson, Michelle Gunn and Jane Angel.
- 13 Collen, M. PAIN Exhibit available from [www.painexhibit.com](http://www.painexhibit.com)

- 14 'Can you Feel My Pain' a European Health Awareness Campaign run by Pfizer. <http://www.flickr.com/groups/can-you-feel-my-pain/>
- 15 Although there are many such as Lakoff/ Johnson, Derrida and Richards who argue that language is in essence metaphorical, '*the omnipresent principle of all its free action*'. (Richards 1938)
- 16 Other examples might be the 'face' of a watch or the 'foot' of a mountain, interestingly all located in the body.
- 17 <http://facial-neuralgia.org/coping/express/demonkiss.html>, accessed 17.09.99
- 18 Rosa Sepple is a visual artist, member of the RI and TN sufferer.
- 19 <http://facial-neuralgia.org/coping/express/demonkiss.html> accessed 17.09.99
- 20 Pain has an element of blank;  
It cannot recollect  
When it began, or if there were  
A day when it was not.
- It has no future but itself,  
Its infinite realms contain  
Its past, enlightened to perceive  
New periods of pain.
- 21 *White silence* by Jack London. London himself is known to have suffered from alcoholism, liver and kidney disease and depression.
- 22 See also Kress and van Leeuwen, 2006 and Macken-Horarik, 2004.
- 23 Alphonse Daudet poet (1840 – 1897) suffered from syphilis for most of his adult life. For the last twelve years of his life he kept a notebook recording the development and effect of his disease, including descriptions of alarming treatments and intense debilitating pain. It was first published as '*In the Land of Pain*' by his widow in 1930, translated

into English in 2002 by Julian Barnes, published by Jonathan Cape, London.

- 24 American feminist poet and scholar . When asked by *Contemporary Authors* to describe what she wrote about, she answered when people didn't know her work and asked that question she would say '*love, sex, death, violence, family, politics, religion, friendship, painters and painting, the body in sickness and health. Joy and pain*'.
- 25 In her series of prints '*Transience*' Susan Aldworth etched directly from actual brain tissue. The prints have been exhibited along with a film exploring identity and the transience of self at GV art Gallery, London in July 2013. Collaborating with Professor David Dexter, Scientific Director of the Parkinson's UK Brain Bank Aldworth and Dexter hope the exhibition will raise awareness of research into brain conditions such as Parkinson and lead to more people donating brain tissue for research purposes. Much of Aldworth's work has engaged with the brain and an exploration of identity and self, and this work stretches the boundaries of her practice and her experimentation with etching.
- 26 Artist Johanna Willenfelt (*University of Gothenburg*) described pain as a material with which she works in her presentation '*Documenting Bodies: Pain Surfaces*' at a conference entitled *Pain as Emotion; Emotion as Pain* organised by the Pain Project, Birkbeck College, London in November 2012.
- 27 Martin worked for many years with Jo Spence, developing their technique of 'phototherapy', see Martin & Spence 1987.
- 28 Interesting comparing this to Aristotle's definition of metaphor to 'bear across'.
- 29 For a fuller discussion of Gell and art as *relational* and the *index* please see chapter three, page 224.

30 Inahara (2013) discusses Wittgenstein's idea of a '*private language*' as an expression in which '*the individual words of this language are to refer to what can only be known to the person speaking to his immediate private sensations. So another person cannot understand the language*'. (Wittgenstein 1953 (1997) p 243) She identifies Wittgenstein's consequent argument that a private language is therefore impossible as a language which only makes sense to one person is not a language, language is by definition inter-subjective. She points out that our contact with the psychological states of another, including pain, are dependent upon a natural reaction to bodily expression, arguing that for Wittgenstein we know pain not only from our own experience but from our relation with others, claiming that his work on the '*relationship between expression and embodiment, on the embodied features of emotion and on its communication is significant for a better understanding of how we communicate about pain*.' (Inahara 2013 p 182).

## NOTES: CHAPTER 2

- 1 Jeff Wall is a Canadian lens based artist whose work constructs realities we easily believe in, but on closer inspection leaves us questioning them and our own preconceptions.
- 2 Thomas Demand is a lens based artist whose work explores notions of reality and representation. Constructing artificial scenes and environments out of card or paper from newspaper or found images he re-photographs and re-presents them.
- 3 Sarah Pickering is a UK lens based artist whose work questions notions of 'authenticity' and 'reality'.
- 4 The Thematic Apperception Test (TAT) was a projective test of personality developed by American psychologist Christiana Morgan and psychoanalyst Henry Murray in the 1930's at the Harvard Psychological Clinic. The cards are a series of images (32 cards) depicting a variety of scenarios which are both provocative and ambiguous. Patients are asked to tell a story in response to one, giving ideas for what has led up to the event shown, what is happening in the image etc. The responses are meant to reveal emotional conflict and the presence or absence of certain mental health conditions. To a contemporary eye the scenarios depicted appear dated and gendered. Murray's thinking was that ambiguous situations would be interpreted in relation to individual's past experience and their defenses to the interrogator would be lowered so that they would not realise how much sensitive information they were revealing. Later they were also used in personal development. As projective instruments the PAIN CARDS bear a slight similarity to the TAT. However the PAIN CARDS are not aimed at reducing interpretations to diagnoses, or revealing information the sufferer would rather not, but rather at promoting a collaborative exploration by patient and clinician which could uncover new information relevant to their pain.



- 5 Borrowing from eighteenth century surgeon-anatomist William Hunter, who first coined the term *Necessary Inhumanity*, which he urged his students to obtain through dissecting the dead. The original quote is from Hunter's lecture to new students: *Anatomy is the basis of Surgery: it informs the head, guides the hand, and familiarizes the heart to a kind of necessary Inhumanity.*' (Hunter c1780).
- 6 Earlier, however with the painting of the *raft of the Medusa* in 1819 Gericault had chosen to minimise the physical signs of suffering , preferring instead to heroize his figures emphasising the muscularity of their bodies and using rather romanticised and dramatic gestures evocative of Hellenistic depictions of suffering such as the Laocoon, which idealized the suffering of their protagonists. (Karakas S. p 94 in Giordano 2011) What was new in this work, as Karakas points, out was the elevation of the suffering of ordinary people to the status of subjects worthy of depiction in art (ibid p 94). Exactly what emotion Laocoon is demonstrating is the subject of much debate within the writing of Griselda Pollock in the 1990's, pointing to issues of ambiguity and legibility within the representation of emotion as a key issue.
- 7 For example Richer's '*Synoptic table of the major hysterical attack*' – Paul Richer, *Etudes cliniques sur l'hystero-epilepsie ou grande hysteria*, Paris: Adrien Delahaye et Emil Lecrosnier, 1881, cited in Hustvedt 2011 p 25.
- 8 Also one of the three protagonists of Hustvedt's book, *Medical Muses* (2011).
- 9 Trigeminal Neuralgia, a neuropathic disorder originating from the trigeminal nerve, causing episodes of intense pain down one side of the face.
- 10 The mechanism of human physiognomy, or electro-physiological analysis of the expression of passions, applicable to the practice

of the plastic arts.

- 11 Charles Darwin's *The Expression of Emotions in Man and Animals* was first published in 1872
- 12 For a fuller discussion of Tracey's work using fMRI's to assign physiological or psychological root causes please see chapter one, pages 49 -51.
- 13 Interestingly though in a recent film, *fragmented lines* Padfield & Omand 2012, Helen and I co-created with pain sufferers for the Science Museum's exhibition *Pain/Painless*, one of the participants referred in interview to '*the lunatic places pain takes you to.*'
- 14 Muybridge's study of 'gait' in a case of locomotor ataxia, from Francis X. (ed Dercum, (1895) , *A Textbook on Nervous Diseases*, Philadelphia: Lea, cited Gilman S. 1996 p 197.
- 15 The entire paper is published for the first time in Gilman's book (1976) *The Face of Madness, Hugh W. Diamond and the Origin of Psychiatric Photography*. See bibliography for full reference. The manuscript of this paper, in Diamond's handwriting, can be found in the archives of the Royal Society London, ref A.P. 38.22.
- 16 The same could be said of artist Mark Gilbert's work with patients with facial difference following surgery (Saving Faces project) – however his medium is that of paint and not lens based – does this make a difference to the questions raised? For full description of this project and Gilbert's work see bibliography for Aita, A., Lydiatt, W. M., Gilbert M. (2012)
- 17 Musee de la prefecture de Police, de Paris, 4 rue de la Montagne Sainte-Genevieve, Paris V.
- 18 Interestingly Annie Cattrell's sculpture of the pain and pleasure pathways of the brain, (*Pain/Pleasure*, Cattrell 2010) provides a

tangible visualisation of the way these overlap during either painful or pleasurable experience. Cattrell worked with cognitive neuroscientist, Prof Kringelbach from Oxford University,<sup>19</sup> to produce a virtually modeled 3D sculpture, using clinical data from magnetoencephalography (MEG) and deep brain stimulation (DBS ), demonstrating the inter-connectivity between pleasure and pain processing.

- 19 See Kringelbach M. L. ( 2009) *Pleasures of the Brain*, Snell Communications, and Kringelbach M. L. (2009) *The Pleasure Center*, OUP.
- 20 See GV Art E-Catalogue for Experiments Exhibition 2010, accessed via [www.gvart.co.uk/press/Experiments\\_E-Catalogue.pdf](http://www.gvart.co.uk/press/Experiments_E-Catalogue.pdf) on 23.07.12
- 21 Phantom Limb Pain It is part of the subject matter of a new exhibition at the Science Museum, London, entitled Pain, Sense, Senseless (Autumn 2012) and one of the components which most fascinates the adult participatory pain group who are co-curating the exhibition, with whom I also worked with artist Helen Omand to make a film.
- 22 See also Kaja Silverman's *Beyond the Threshold of the Visible*.
- 23 Wright has continued investigating the experience of pain collaborating with Dr Charles Pither and Dr Anita Holdcroft (with input from Dr Mick Serpell and the late Patrick Wall), playwrights Diane Samuels and Sarah Woods and performer Cathrine Long to create *PUSH*, performed at the People Show Theatre in 2003. *PUSH*<sup>24</sup> uses visual filmed clips of physical endurance and visual metaphors of mountain climbing to suggest to the audience the extreme sensation people with pain experience. It also includes filmed interviews with the late Patrick Wall and with anaesthetists/pain specialists Dr Charles Pither and Dr Anita Holdcroft. The physical environment created for the performance aimed at disorientating the audience into a first hand experience

of the disorientation which chronic pain effects. She has collaborated with many scientists and medical professionals since, working closely with people with various medical conditions or disabilities but the overriding focus of her investigations appears to remain that of human identity and exchange.

24 *PUSH* is a multi media performance of approximately 75 minutes which 'charts the rational and irrational responses of people caught in a state of unexplained physical suffering' (alexawright.com accessed 22<sup>nd</sup> August 2012).

25 However the 'window of the soul' notion unfortunately seems firmly implanted in the minds of our facial pain workshop participants; the fact that they feel singled out for there to be a disconnect between the apparent window to their soul and their own soul or as I would see it, sense of identity, is one of the reasons they suffer.

26 See <http://art.tfl.gov.uk/projects/detail/1632> and [http://www.drydengoodwin.com/linear\\_documentation.htm](http://www.drydengoodwin.com/linear_documentation.htm)

27 Associate Professor of Art History, Florida Gulf Coast University.

28 The legendary Trojan priest Laocoon warned the Trojans of the wooden horse containing the Greek soldiers. The sculpture, dating from approx 100 BC depicts him and his sons struggling with deadly snakes which Apollo has sent to strangle him for his betrayal.

29 The technical challenges were not easy for me to overcome and I had incredible support from Helen Omand who patiently helped me edit, and for which I am incredibly grateful.

30 In '*Simbodies and Nobodies*' (2010), Borland describes how during her teaching within medical schools working with artificial manikins ie simulated bodies, she was interested as an artist in

how consideration of the blatant 'non-aesthetic' form of the manikins, rather than their function,' dominated her sensibilities. She describes how:

*'The body of work grew from this anxiety and an awareness that neither medical students nor their tutors found it easy to engage with the manikins on any meaningful emotional level. Moving away from the flesh tone vinyl 'life like' qualities in the originals by using film and casting in wax and plaster, my works attempt to reach a level of intimacy, which is not afforded the manikins in daily use, raising the question: can visual art introduce an aesthetic and feeling dimension into a potentially artificial and stilted learning situation?'* (Borland 2010).

- 31 The revised *duet for pain* (2012) was shown at the Wellcome Trust at the Birkbeck/Wellcome Trust conference *Pain and its Meanings* in December 2012 and at the Narrative Medicine Conference at King's College London in June 2013.
- 32 Ayesha Ahmad: On **Mask:Mirror:Membrane**, an exhibition by Deborah Padfield: <http://blogs.bmj.com/medical-humanities/2011/07/27/ayesha-ahmad-on-maskmirrormembrane-an-exhibition-by-deborah-padfield/>
- 33 Denna Jones: Review of the **Mask:Mirror:Membrane** exhibition in the perspectives section of the Lancet [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61196-3/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61196-3/fulltext)

### NOTES: CHAPTER 3

- 1 For a fuller discussion of the imperative for more democratised dialogue within medical practice see Bleakley 2013.
- 2 An exhibition of new work exploring alternative forms of self-representation and portraiture by Faisal Abdu'Allah and the Chasing Mirrors Collective, a group of young people from Arabic-speaking communities in Brent, Barnet and Ealing.
- 2b It is also interesting that the main metaphoric categories for descriptions of pain identified by Biro and Semino are reflected in many of the co-created images, for example mirror metaphors and injury metaphors such as swords, scalpels, glass and knives.
- 3 For further discussion of a mixed method approach see Punch (1999) and Burke et al (2004).
- 4 For an expanded discussion of this idea see Napier 2013.
- 5 See also for comparison Frida Kahlo's description within her diaries of an image of Janus looking to the right towards the future visualising disaster depicted as herself integrated into the top of a broken column with the words 'I am disintegration' (Kahlo 1995, plate 41 page 225).
- 6 Compare Frank's (1997) writing of his vision of frosted glass illuminated at night when he cannot sleep because of pain, and the way he describes using pain to make something possible.
- 7 In *Mourning and Melancholia* Freud (1917) has written extensively on the symbolism of the shadow, the effect of our past on our present, and the challenge of loss.
- 8 This was part of a new piece of visual work I wanted to make juxtaposing interpretations from different disciplinary perspectives with the original meaning for the co-creator and sufferer.
- 9 Additionally there is their potential circulation in the medical and medical humanities literature.

10 According to Gell 'An agent is one who 'causes events to happen' in their vicinity.' (Gell 1998 p 16).

11 Of the importance of clinician's language, Prof Zakrzewska states in the film ***duet for pain*** (Padfield 2012) '*The language we as clinicians use sometimes is inducing problems, because it causes harm as well and that is what is brought out beautifully in narrative medicine.*'

12 For discussion of the politics of language, see Wetherell (2009).

13 The first linkograph Fig 91, LINKOGRAPH CA1 was independently analysed by myself and Tamer El-Khouly, a PhD Candidate at the Bartlett School of Architecture, UCL, and then integrated. The second, Fig 92, was independently analysed by myself and Helen Omand. It is useful for more than one person to develop the linkograph as deciding which speech components count as utterances or ideas, and to which ideas they link, is interpretive. Negotiating these definitions with a collaborator ensures as much objectivity as possible within a necessarily interpretative process.

14 Compare with Emily Dickenson's poem:

Pain has an element of blank;  
It cannot recollect  
When it began, or if there was  
A time when it was not.  
It has no future but itself,  
Its infinite realms contain  
Its past, enlightened to perceive  
New periods of pain.

Taken from: Todd ML, Higginson TW (eds) (1980) *Collected Poems of Emily Dickenson*, New York, Avenal (First published 1890)

15 Compare with Caliban's lines in Shakespeare's *Tempest*:

...if he awake,  
From toe to crown he'll fill our skins with pinches,  
Make us strange stuff.

(Act IV, Scene I, I 1975)

# BIBLIOGRAPHY

## Personal Communication:

Bourke, J. (2011 b) interview with Deborah Padfield 20.10.11

Burgin, V. (2010) Personal communication

Dennett, T. (2011) interview with Deborah Padfield

Dennett, T. (2011) personal communication

Dwoskin, S. (2001a) personal communication

Dwoskin, S. (2001b) interview with Deborah Padfield 2001

Eccleston, C. (2012) *A Normal Psychology for Pain*, Plenary Lecture presented at the British Pain Society Annual Scientific Meeting, Liverpool: delivered 27<sup>th</sup> April 2012

Goodwin, D. (2001) personal communication

Mathews, T (2010) personal observations at the Irigaray Conference, Slade, UCL) See also: Mathews, T. (2007) 'Touch, translation, witness in Alberto Giacometti, La Main, Le Nez'. *French Studies*, 61 (4): pp. 447-459.

Pither, C. (2002) personal communication

Semino, E. (2013) personal communication

Warner, M. (2012) lecture at the RCA, Wed 21<sup>st</sup> Nov 2012)

Wildgoose, J. (2012) Personal communication

Zakrzewska, J. M. (July 2011) Medical intro panel for MMM exhibition, Menier & UCLH Street Galleries, London

Zakrzewska, J. M. (2013) personal communication



## Data/Material from projects:

### ***Perceptions of Pain:***

Participating patients' testimonies and images from ***perceptions of pain***

### ***face2face:***

Participating patients' testimonies and images from ***face2face***

NPG Workshop, patient journey and recorded consultation evaluation forms

Transcript from NPG workshop discussions 05.11.09

Ozarovsky, F. (2011) interview in film, ***facing pain*** (Padfield 2012)

Ozarovsky, F. (2012) interview in film, ***duet for pain*** (Padfield 2012)

Zakrzewska J., (2011) interview in film, ***facing pain*** (Padfield 2012)

Zakrzewska J. (2012) interview in film, ***duet for pain*** (Padfield 2012)

## **Web Sources:**

Ahmad, A. (2011) <http://blogs.bmj.com/medical-humanities/2011/07/27/ayesha-ahmad-on-maskmirrormembrane-an-exhibition-by-deborah-padfield/> accessed 08.07.11

Collen, M. R (2006), PainExhibit.com, accessed 22.07.11

Collen, M. R. (2001) *Chronic Pain*, Image:<http://www.painexhibit.com/about>

Jones, D. (2011) [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61196-3/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61196-3/fulltext)

Sandmeir D. (<http://facial-neuralgia.org/coping/express/demonkiss.html>, accessed 17.09.09)

Wright, A. (2012) alexawright.com, accessed 22nd august 2012

(<http://www.helpmego.to/ica/icaweb/imaginaria/wright1.html> sourced 24.07.12)

## References:

- Abse, D. (1984) 'The Stethoscope' in *Literature and Medicine* (3), pp.19.
- Aiken, C. (1930) 'The Room', in *Aiken's Collected Poems*, reprinted 1970. Oxford: Oxford University Press.
- Aita, A., Lydiatt, W. M. and Gilbert, M. (2010) 'Portraits of care: medical research through portraiture', *BMJ Humanities*, June.
- Aldersey-Williams, H., Arnold, K., Gordon, M., Kotsopoulos, N., Peto, J. and Wilkinson, C. (eds) (2009) *Identity & Identification*, London, Black Dog Publishing.
- Aldrich, S. and Eccleston, C. (2000) 'Making sense of everyday pain', *Social Science and Medicine* 50, 11, pp.1631-41.
- Arends, B. and Thackara, D. (2003) (eds) *Experiment: conversations in art and science*, London: Wellcome Trust.
- Arnold, K. and Peto, J. (eds) (2009) Introduction to *Identity & Identification*, Arnold et al (eds) London: Black Dog Publishing.
- Attridge, D. (1997) 'Roland Barthes's Obtuse and Sharp Meaning and the Responsibilities of Commentary' in Rabate, J. (ed) *Writing the Image After Roland Barthes*, Philadelphia: University of Pennsylvania Press.
- Auden W H (1966 this ed. 1969) *Collected Shorter Poems, 1927-1957*, London: Faber and Faber
- Bachelard, G. (1958 1<sup>st</sup> ed, this edition 1992) *The Poetics of Space*, Jolas, M. (tr) Boston: Beacon Press
- Bakhtin, M. (1986) *Speech Genres and Other Late Essays*, McGee V. W. (tr) Texas: University of Texas Press
- Barnes, J. (2002) (ed/trans) Alphonse Daudet, *In the Land of Pain*, London: Jonathan Cape
- Barth, F. (1969 this ed. 1998) *Ethnic Groups and Boundaries, the social organization of cultural difference*, Long Grove IL: Waveland Press
- Barthes, R. (1964) *Image-Music-Text*, 1977 edition, London: Fontana.
- Barthes, R. (1970) *The responsibility of forms: Critical essays on Music, Art, and Representation*, Trans. Richard Howard (1985). New York: Hill and Wang.
- Barthes R (1977) *A Lover's Discourse, fragments*, 1990 edition, London: Penguin.
- Barthes, R. (1980) *Mythologies*. London: Paladin.
- Barthes, R. (1993) *Camera Lucida*. UK: Vintage.

- Bass C, Jack T. (2002) Current approaches in chronic pain. *Clin Med*; 2:505-8.
- Bate, D. (2009) *Photography, the key concepts*. Oxford: Berg.
- Beck, B. (1978) 'The metaphor as a mediator between semantic and analogic modes of thought', *Current Anthropology* (19/1), pp. 83-87.
- Bennett, M. I., Attal, N., Backonja, M. M., et al (2007 ) Using screening tools to identify neuropathic pain, *PAIN*, 127; pp 199-203
- Benjamin, W. (1936) 'L'œuvre d'art à l'époque de sa reproduction mécanisée' in Alcan, F. *Zeitschrift für Sozialforschung* Jahrgang V, Paris, pp. 40–68.
- Berger, J. (1972) *Ways of Seeing*, London: Penguin.
- Berger, J. (1980) *About looking*, London: Writers and Readers Publishing Cooperative Ltd.
- Berger, J. (1992) *Keeping a Rendezvous*, 1993 edition, London: Granta Books.
- Berger, J. and Mohr, J. (1982) *Another way of telling (on photography)*, New York: Pantheon.
- Berger, J. (1984) *and our faces, my heart, brief as a photo*, London: Pantheon Books, Random House
- Biernoff, S. (2002) *Sight and Embodiment in the Middle Ages*, Basingstoke: Palgrave Macmillan.
- Biro, D. (2010) *The Language of Pain. Finding words, compassion and relief*. New York: WW Norton and Co.
- Biro, D. (2011) 'Redefining pain', *Palliative and Supportive Care* 9, pp.107–110.
- Bleakley, A., Marshall, R. and Brömer, R. (2006) 'Toward an aesthetic medicine: developing a core medical humanities undergraduate curriculum', *Med Humanit* (27), pp. 197–213.
- Bleakley, A. (2010) Introduction to Medical Humanities Association Conference publication, Truro.
- Bleakley, A. and Marshall, R. J. (2012) 'The embodiment of lyricism in medicine and Homer', *Med Humanit* (38), pp. 50–4
- Bleakley, A. Bligh, J. Browne, J. (2011) *Medical Education for the Future: Identity, Power and Location*, in *Advances in Medical Education*, Volume 1 ed Hamstra, S. J. Heidelberg, London, New York: Springer.
- Blyth, F.M., March, L.M., Brnabic, A.J.M., Jorm, L.R., Williamson, M. and Cousins, M.J. (2001) 'Chronic pain in Australia: a prevalence study', *Pain* 89, pp.127–34
- Bollas, C. (1992) *Being a character: Psychoanalysis and self experience*. New York: Hill and Wang.

- Borland, C. (2006) *Preserves*, Edinburgh: The fruitmarket gallery.
- Bourke, J. (2011a) *Pain and the Politics of Sympathy, Historical Reflections, 1760's to 1960's*, Inaugural address as Treaty of Utrecht Chair, University of Utrecht Press delivered on 8<sup>th</sup> June 2011.
- Bourneville, D. M. (1876-1877) preface to the first volume of the *Iconographie photographique de la Salpetriere* 1: Paris
- Bourriaud, N. (2002) *Relational Aesthetics*. Trans. Pleasance, S. and Woods, F. with the participation of Copeland: Les presses du reel.
- Bradbury, K. (2011) 'Thinking about pain: How do our thoughts impact on our pain experience', *Pain News* (Winter), pp. 40
- Bradley, F. (2006) intro to Borland, *Preserves*, Edinburgh: The fruitmarket gallery.
- Broks, P. (2004) 'The sounds of a chiming clock, pain, perception and the person', in *Pain Passion, Compassion, Sensibility*. Wellcome Trust Exhibition Catalogue London for the Science Museum, London: Wellcome Trust.
- Brody, H. (1987) *Stories of sickness*. New Haven, Connecticut: Yale University Press.
- Broks, P. (2009) in (eds) Aldersey Williams, H., Arnold, K., Gordon, M., Kotsopoulos, N., Peto, J. and Wilkinson, C. London, *Identity and Identification*, Black Dog Publishing Ltd for the Wellcome Collection p 80.
- Bronte, E. (1847) *Wuthering Heights*, 1983 edition, London: Everyman's Library, Dent.
- Brown, C. (2008) 'The lived experience of chronic pain: evidence of people's voices', in Rashiq, D., Schopflocher, D., Taenzer, P. and Jonsson, E. (eds), *Chronic pain: a health policy perspective*, Weinheim: Wiley.
- Brushfield, T. N. (1857) *The Photographic Journal* 3, 289.
- Berger, J. (1980). Understanding a photograph. In A. Trachtenberg (Ed.), *Classic essays on photography*. New Haven, CT: Leete's Island Books.
- Burgin, V. (1976) 'Art, Common Sense and Photography', London: *Camera Work* 3
- Burgin, V (ed). (1982) *Thinking Photography*, London: Macmillan.
- Burgin, V. (1982). Looking at photographs. In V. Burgin (Ed.), *Thinking photography*. London: Macmillan.
- Burgin, V. (1999) 'Art, Common Sense and Photography', in Evans, J. and Hall, S. (eds), *Visual Culture: the reader*. Sage Publications.

Burke Johnson, R. and Onwuegbuzie, A.J. (2004) 'Mixed Methods Research: A Research Paradigm Whose Time has Come', *Educational Researcher* 33, pp.14-25.

Burney, F. (1986) in Hemlow J. (ed) '*Selected Letters and Journals*', Oxford: Clarendon Press.

Cabanac, M. (2005) '*Pleasure and Pain*' in Carr, D., Loeser, J. and Morris, D. (eds) '*Narrative Pain and Suffering: Progress in Pain Research and Management Vol 34*'. Seattle, USA: IASP Press

Campbell, J. (1985) 'Primitive Mythology', *The Masks of God* (1), Middlesex: Penguin.

Cole, T. and Carlin, N. (2011) 'Maldynia as muse: A recent experiment in the visual arts and medical humanities', in Giordano, J. (ed.) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*, New York: Taylor & Francis.

Carr, D., Loeser J. and Morris D. (eds) (2005) '*Narrative Pain and Suffering: Progress in Pain Research and Management Vol 34*', Seattle, USA: IASP Press.

Case, C. and Dalley, T. (2002) *The Handbook of Art Therapy*, London: Routledge.

Cassell E. J. (1982) 'The Nature of Suffering and the Goals of Medicine', *The New England Journal of Medicine*, 306/11, pp. 639-645.

Cervero, F. (2012) *Understanding Pain, Exploring the Perception of Pain*, Cambridge Mass: MIT Press.

Chambers E. (2002) *Henry Tonks: Art and Surgery*, London: The College Art Collections, UCL.

Chandler, D. (2012) 'Helen Sear: Seeing in the Dark' in Sear H, *Inside the View*, Cardiff: Ffotogallery.

Chapman, C.R., Nakamura, Y. and Flores, L.Y. (1999) 'Chronic pain and consciousness: a constructivist approach', in Gatchel, R.J. and Turk, D.C. (eds) *Psychosocial factors in pain*. New York: Guildford pp. 45.

Charcot, J. M. (1880) Hospice de la Salpetriere: Recouverture des conferences cliniques de M. Charcot, in *Progres Medical* 8 (November 27, 1880): 970. Cited by Shorter E., (1992) in *From Paralysis to Fatigue: A History of Psycosomatic Illness in the Modern Era*, New York: Free Press, p 169 cited in Hustvedt (2011) p 12

Charcot, J.M., Richer, P. (1989) *Les Difformes et les malades dans l'art*, Paris: Lecrosnier et Babe, v-vi

Charon, R. (2001a) 'What narrative competence is for', *The American Journal of Bioethics* 1(1), pp.62-3.

- Charon, R. (2001b) 'The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust', *Journal of the American Medical Association* 286, 15/1, pp.897-902
- Charon, R. (2001c) 'The patient-physician relationship', *Journal of the American Medical Association*, [www.jama.com](http://www.jama.com) (accessed 1<sup>st</sup> Nov 2008)
- Charon, R. (2002) "Narrative medicine: form, function, and ethics". *Annals of Internal Medicine*, 134/1, pp.83-7
- Charon, R. (2005 a) 'A Narrative Medicine for Pain', in Carr D., Loeser J. and Morris D. (eds) *Narrative Pain and Suffering: Progress in Pain Research and Management* Vol 34. Seattle, USA: IASP Press
- Charon, R. (2005 b) 'Bearing witness--Sontag and the body', *The New England Journal of Medicine* 352/8, pp.756- (rest of page no?)
- Charon R. (2006) *Narrative Medicine: honoring the Stories of Illness* Oxford, Oxford University Press
- Charon, R. (2008) 'Right brain: reading, writing, and reflecting: making a case for narrative medicine in neurology', Alcauskas M, *Neurology* 70(11), pp.891-4 (if this is a journal, who is *Alcauskas M*? can delete as don't need editor of journal)
- Charon, R. (2010) 'Commentary: calculating the contributions of humanities to medical practice-motives, methods, and metrics', *Academic Medicine* 85(6), pp.935-7
- Chrysostomou, C.C. Maguire, K. Zakrzewska, J. M. (2004) Expression of Pain Using Existing Works of Art, British Pain Society Conference
- Charon R (2009) in Radley, A. *Works of Illness: Narrative, Picturing and the Social Response to Serious Disease*, Ashby-de-la-Zouch: InkerMen Press
- Cole, F., Macdonald, H., Carus, C., Howden-Leach, H. (2005) *Overcoming Chronic Pain, A self-help guide using Cognitive Behavioral Techniques*, London: Constable & Robinson
- Cole, J. with Spalding, H. (2009) *The Invisible Smile, Living without facial expression*, Oxford: Oxford University Press
- Cole, T. and Carlin, N. (2011) 'Maldynia as muse: A recent experiment in the visual arts and medical humanities', in Giordano. J. (ed.) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*, New York: Taylor & Francis
- Conrad R, Schilling G, Bausch C, et al. (2007) Temperament and character personality profiles and personality disorders in chronic pain patients. *Pain*, 133:197-209.
- Crane, S (1970) 'The Open Boat: A Tale intended to be after the Fact. Being the Experience of four men from the Sunk Steamer Commodore', in Bowers, F. (ed) *The Work of Stephen Crane*. Charlottesville: University Press of Virginia

- Creswell, J.W., Fetter, M.D., and Ivankova, N.V. (2004) 'Designing a mixed methods study in primary care'. *The Annals of Family Medicine* 2, pp.7-12
- Darwin, C., (1872) *The Expression of Emotions in Man and Animals*, (ed with introduction, afterword and commentaries by Paul Ekman, London: Fontana Press 1999
- Daudet, A. (2002, 1<sup>st</sup> published 1930) *In the Land of Pain*. Edited and translated by Barnes, J., London: Johnathan Cape, Random House.
- Davies KA., Macfarlane GJ., McBeth J., Morriss R., Dickens C. (2009) Insecure attachment style is associated with chronic widespread pain. *Pain*;143:200-5.
- Deignan, A., Littlemore, J. and Semino, E. (2013) *Figurative Language, Genre and Register*, Cambridge: Cambridge University Press.
- Delahaye, A., Lecrosnier, E. (1881) Paul Richer, Etudes cliniques sur l'hystero-epilepsie ou grande hysteria, cited in Hustvedt 2011 p 25.
- Dennett, T. (2011) Jo Spence's auto-therapeutic survival strategies in Bell, S. and Radley, A. (eds) 'Representations of illness and disease', *Health* 15(3), pp.223 -239.
- De Souza, L. H. and Frank, A. O. (2000) 'Subjective pain experience of people with chronic back pain', *Physiotherapy Research International* 5/4, pp. 207-19.
- Van Dijck, (2005) *The Transparent Body, a cultural analysis of medical imaging*. Seattle: University of Washington Press.
- Dickenson, E. (1890) *After great pain a formal feeling comes*, in Hartnoll, E. (ed) (1994) *The Selected Poems of Emily Dickinson*, Hertfordshire, Wordsworth Editions.
- Dickenson E. (1890's) *Pain has but one Acquaintance* in Hartnoll, E. (ed) (1994) *The Selected Poems of Emily Dickinson*, Hertfordshire, Wordsworth Editions
- Dickenson E. (1890's) *There is a pain so utter* in Hartnoll, E. (ed) (1994) *The Selected Poems of Emily Dickinson*, Hertfordshire, Wordsworth Editions
- Dickenson E. (1890's) *Pain has an element of blank* in Hartnoll, E. (ed) (1994) *The Selected Poems of Emily Dickinson*, Hertfordshire, Wordsworth Editions
- Didi-Huberman, G. (2003) *Invention of Hysteria: Charcot and the Photographic Iconography of the Salpetriere*, (translated by Hartz, A.,) Cambridge Massachusetts: MIT.
- Duchenne de Boulogne, G. B. (1862a) Album de photographies complementaires pathologique du livre intitul De l'electrisation localisee, Paris: J. B. Balie (tr and ed) Cuthbertson, A. (1990) *The Mechanism of Human Facial Expression*, Cambridge: Cambridge University Press.
- Duchenne de Boulogne, G. B. (1862b) *Mecanisme de la Physionomie Humaine*, Paris: J. B. Balie (tr and ed) Cuthbertson, A. (1990) *The Mechanism of Human Facial Expression*, Cambridge: Cambridge University Press.

- Durden, M. (2003) *Negotiating Difference: The Transactions of Portraiture* in Newton K & Rolph C. *Masquerade*, (2003) Cardiff: Ffotogallery.
- Ede, S. (2000) (ed) *Strange and Charmed, Science and the Contemporary Visual Arts*, London: Calouste Gulbenkian Foundation.
- Ede, S. (2005) *Art & Science*, reprinted 2008, London: IB Taurus.
- Eisenberger, N.I., Lieberman M.D., and Williams K.D. (2003) 'Does rejection hurt? An fMRI study of social exclusion'. *Science* 302/5643, pp.290-92
- Elkins, J. (1999) *Pictures of the body: Pain and metamorphosis*. Stanford: Stanford University Press
- Ewing, W. A. (2008) *FACE The New Photographic Portrait*, London: Thames & Hudson
- Fairley, P. (1982) *The Conquest of Pain*, London: Michael Joseph.
- Feit Covey, R. (2011) 'Maldynic Pain in Image and Experience, Engraving Meaning through Subtraction', in Giordano, J. (ed.) (2011) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*, New York: Taylor & Francis.
- Fillingim RB, Ohrbach R, Greenspan JD, et al. (2011) Potential psychosocial risk factors for chronic TMD: descriptive data and empirically identified domains from the OPPERA case-control study. *J Pain*; 12:T46-T60.
- Finestone, H. M. (2009) *The Pain Detective, Every Ache Tells A Story*, Santa Barbara, California, Denver, Colorado and Oxford England: Praeger
- Fitzgerald, M (2004a) 'Painful beginnings', in *Pain* 110/3, p 508
- Fitzgerald, M (2004b) 'Dissecting pain', in *Pain, Passion, Compassion, Sensibility*, a Wellcome Trust CD Exhibition Catalogue: The Science Museum, London.
- Fitzgerald, M. and MacDermott A (2005) 'The development of pain systems', in Hunt, S. P. and Koltzenburg, M. (eds) *The Neurobiology of Pain*. Oxford: Oxford University Press
- Fitzgerald, M. (2006) 'Long-term consequences of early infant injury and trauma upon somatosensory processing', *European Journal of Pain* 11/7, pp.799-809
- Fletcher, J. (2003) 'Sweet Liberties: Narratives of Resistance and Desire' in (eds) Kate Newton and Christine Rolph (2003) *Masquerade: Women's Contemporary Portrait Photography*, Ffotogallery Publishing: Cardiff
- Forceville, C. (2008) 'Metaphor in pictures and multimodal representations', in Gibbs, R.W.Jr. (ed) *The Cambridge Handbook of Metaphor and Thought*, Cambridge: Cambridge University Press, pp.462-82
- Foucault, M. (1963) *The Birth of the Clinic, An Archaeology of Medical Perception*, reprinted 1997, translated by Sheridan, A. M., London: Routledge



Frank, A.W. (1997) *The Wounded Storyteller, body, illness and ethics*, Chicago: University of Chicago Press

Freud, S. (1917) 'Mourning and Melancholia. *The Standard Edition of the Complete Psychological Works of Sigmund Freud*', Volume XIV (1914-1916), On the History of the Psycho-Analytic Movement, Papers on Metapsychology and Other Works, pp.237-258 London: Hogarth

Gell, A. (1998) *Art and Agency, An Anthropological Theory*, New York, Oxford: Clarendon Press

Gell, A. (2006) *The Art of Anthropology: Essays and Diagrams*, Oxford: Berg

Geller, B. (2011) The PainT project, *Pain News* Winter 2011, pp.42

Gero, J. S. and Lindemann, U. (eds), (2005) *Human Behaviour in Design 05*, Sydney: Key Centre of Design Computing and Cognition, University of Sydney

Gilman, S. (1976) (ed) *The Face of Madness, Hugh, W. Diamond and the Origin of Psychiatric Photography*, New York: Brunner/Mazel

Gilman, S. (1996) *Seeing the Insane*, Nebraska: University of Nebraska Press

Giordano, J. (ed), (2011) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*, New York: Taylor & Francis

Glasser, B. (2010) *Medicinema - Doctors in Films*, Oxford: Radcliffe Publishing

Goffman, E. (1983) 'The interaction order', *American Sociological Review* 48, pp.1-17

Goldschmidt, G. (1990) 'Linkography: assessing design productivity' in Trappl, R. (ed), 'Cybernetics and System '90', *World Scientific*, Singapore, pp. 291-298

Goldschmidt, G. (1992) 'Criteria for design evaluation: a process-oriented paradigm' in Kalay, Y. E. (ed), *Evaluating and Predicting Design Performance*, New York: John Wiley & Son, Inc, pp. 67-79

Goldschmidt, G. (1995) 'The designer as a team of one', *Design Issue* 16(2), pp.189-209.

Goodman, N. (1976) *Languages of Art*, Indianapolis: Hackett

Gray, P. (ed) (1989) 'Sigmund Freud "Charcot"' in *The Freud Reader*, New York: Norton

Greenhalgh, T. and Wengraf, T. (2008) 'Collecting stories: is it research? Is it good research? Preliminary guidance based on a Delphi study'. *Medical Education* 42(3), pp.242-7

Greenhalgh, T and Hurwitz, B. (1999) 'Why study narrative?', *The Western Journal of Medicine*, 170/6, pp.367-9

Gundel, H. and Tolle, T. R. (2005) 'Neurobiology of emotions and pain', in Carr, D., Loeser, J. and Morris, D. (eds) *Narrative Pain and Suffering: Progress in Pain Research and Management* Vol 34. Seattle, USA: IASP Press

Grosz, E. (1994) *Volatile Bodies, Toward a corporeal feminism*, Indiana: Indiana University Press.

Grosz, E. (1995) *Space, time and perversion*, London: Routledge.

Hamilton, P. and Hargreaves, R. (2001) *The Beautiful and the Damned, the creation of identity in nineteenth century photography*, Aldershot: Lund Humphries in association with the National Portrait Gallery.

Harrison, B. (2002) 'Photographic visions and narrative enquiry', *Narrative Enquiry* 12, pp.87-111.

Harrison, B. (2002b) 'Seeing health and illness worlds – using visual methodologies in a sociology of health and illness: a methodological review', *Sociology of Health & Illness* 24 (6), pp. 856-872.

Henriksen N., Tjornhoj-Thomsen, T. and Ploug Hansen, H. (2011) 'Illness, everyday life and narrative montage: The visual aesthetics of cancer in Sara Bro's Diary' in Bell, S. and Radley, A. (eds) *Representations of illness and disease* *Health* 15(3), pp. 277-297.

Hodgkiss, A. (2000) *From Lesion to Metaphor, Chronic Pain in British, French and German Medical Writings, 1800-1914*, Amsterdam, Atlanta, Georgia: Editions Rodopi B.

Hughes, O. (2010) Images of pain: Understanding pain related distress from the viewpoint of semiotics. *British Pain Society Newsletter; PAIN* Summer: 48–50.

Hsu, M., Schubiner, C., Lumley, M., Stracks, J., Clauw D. and Williams, D. (2010) 'Sustained Pain Reduction Through Affective Self-awareness' in 'Fibromyalgia: A Randomized Controlled Trial'. *Journal of General Internal Medicine* 25(10), pp.1064–70.

Hunter W. [circa 1780]. Introductory lecture to students St Thomas's Hospital Manuscript 55: 182. (Historian Ruth Richardson pointed me to this who in turn acknowledges Dr Marion Bowman had kindly brought this manuscript to her attention when she was in Chicago researching her book *Death, dissection and the destitute*.)

Hurwitz, B. (2000) 'Narrative and the practice of medicine', *Lancet* ,356 (9247), pp.2086-9.

Hurwitz, B. (2003) 'Looking at Pain', in Padfield, D. (2003) *Perceptions of Pain*. 1<sup>st</sup> Edition. Stockport: Dewi Lewis Publishing.

Hurwitz, B. (2009) in Radley, A. (2009) *Works of Illness: Narrative, Picturing and the Social Response to Serious Disease*, Ashby-de-la-Zouch: InkerMen Press

Hustvedt, A. (2011) *Medical Muses, Hysteria in Nineteenth-Century Paris*, London: Bloomsbury Publishing

Inahara, M. (2012) 'The Voice of Pain: The Semiotic and Embodied Subjectivity' in Lennon, K., Gonzalez-Arnal, S. and Jagger, G. (2012) (eds) *Embodied Selves*, Basingstoke: Palgrave Macmillan

Imbierowicz K, Egle UT. (2003) Childhood adversities in patients with fibromyalgia and somatoform pain disorder. *Eur J Pain*;7:113-9

- International Association for the Study of Pain Subcommittee on Taxonomy. (1979) "Pain Terms: A List with Definitions and Notes on Usage". *Pain* 6, no 3
- Irigaray, L. (2008) *Sharing the World*, London: Continuum
- Irigaray, L. (2008) *Conversations*, London: Continuum
- Jones, A. (1998) *Body Art: Performing the Subject*. Minneapolis and London: University of Minnesota Press
- Jones D. (2011) *Portraits of Pain*, The Lancet; Vol 378 July 30
- Kan, J. W. T and Gero, J. S (2005) 'Design Behaviour Measurement by Quantifying Linkography in Protocol studies of Designing', in Gero, J. S. and Lindemann, U. (eds), (2005) *Human Behaviour in Design 05*, Sydney: Key Centre of Design Computing and Cognition, University of Sydney
- Kahlo, F. (1995) in Fuentes, C. (ed) *The Diary of Frida Kahlo, An Intimate Self Portrait*, intro by Fuentes, C., London: Bloomsbury Publishing
- Karakas, S. (2011) Expressions of Chronic Pain and Suffering in Western Art in , in Giordano. J. (ed.) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*, New York: Taylor & Francis
- Kenny, D.T. (2004) 'Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm' *Patient Education and Counseling* 52(3), pp. 297–305
- Kemp, S. (2004) *Future face: image, identity, innovation*, London: Profile Books
- Kimberlin, C., Brushwood, D., Allen, W., Radson, E. and Wilson, D. (2004) 'Cancer patient and caregiver experiences: communication and pain management issues', *Journal of Pain and Symptom Management* 28, pp.566–78
- Kirklin D, Richardson R,(eds) (2001) *The Medical Humanities: A Practical Introduction*. London: Royal College of Physicians of London
- Kleinman, A. (1988) *The illness narratives, suffering, healing & the human condition*, USA: Basic Books
- Kleinman, A. (2006) *What Really Matters, Living a Moral Life Amidst Uncertainty and Danger*, Oxford: Oxford University Press
- Kleinman, A. (2008) *Catastrophe and caregiving: the failure of medicine as an art*. *Lancet* 371: 22–23.
- Kosarova, Z. (2011) I, translated by Ticha J & Hoskins S, *Certainly*, Exhibition Catalogue, Galerie Rudolfinum, Prague
- Kosloff, M. (1988) 'Real faces' in *Lone Visions, Crowded Frames: essays on photography*, Albuquerque: University of New Mexico Press 1994 pp 76-78
- Kress, G. R. and van Leeuwen, T. (2006) *Reading images: The Grammar of Visual*
- Kringelback M. L. (2009) *The Pleasure Center*, OUP

- Kristeva, J. (1986) *Revolution in Poetic Language*, tr Roudiez, L. S., New York: Columbia University
- Kugelmann, R. (1999) Complaining about chronic pain. *Soc Sci Med*; 49:1663–76.
- Kuppers, P. (2007) *The scar of visibility: Medical performances and contemporary art*, Minneapolis: University of Minnesota Press
- Lannetti, G. D., Zambreanu, L., Wise, R. G. et al (2005) 'Pharmacological modulation of pain related activity during normal and central sensitization states in humans' *Proceedings of the National Academy of Sciences of the United States of America*, 102/ 50, pp. 18195-18200
- Larratt-Smith, P. (2012) (ed) *Louise Bourgeois: The return of the repressed*, London, Violette Editions
- Lascaratou, C. (2007) *The Language of Pain: Expression or Description*, Amsterdam: John Benjamins
- Lauridsen, P. (1991) The film and the third meaning, *Tryllelygten* 1(1) : 125- 147
- Lennon, K., Gonzalez-Arnal, S., Jagger, G., (2012) (eds) *Embodied Selves*, Basingstoke: Palgrave Macmillan
- Livingston, W. K. (1998) Pain and Suffering (ed. Fields H.) Seattle, IASP Press, pp xvii, 250
- Loeser, J. (2005) 'Pain, Suffering, and the Brain: a Narrative of Meanings', in Giordano, J. (ed) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*. New York: Taylor & Francis
- London, J. (1991) 'The White Silence', in Labor, E., Leitz, R. and Shephard, I. M. (eds) *Short Stories of Jack London*, New York: Collins
- Macfarlane, G.J., McBeth, J. and Silman, A. (2001) 'Widespread body pain and mortality: prospective population based study', *BMJ* 323, pp.662
- Macken-Horarik, M (2004) 'Interacting with the Multimodal Text: Reflections on Image and Verbiage in Art Express', *Visual Communications*, 3 (1), pp.5-26
- Maguire, K. (2012) Being Human and in Pain, *Pain News* 10 (2), pp.115-117
- Marcus, S. (1975) 'Freud and Dora: story, history, case history' in *Representations: Essays on Literature and Society*. New York: Random House, pp 247-310
- Marshall, R. J. and Bleakley, A. (2008) 'Putting it bluntly: communication skills in the Iliad'. *Medical Humanities* 34, pp. 30–4
- Marshall, R. J. and Bleakley, A. (2009) 'The death of Hector: pity in Homer, empathy in medical education'. *Medical Humanities* 35, pp. 7–12
- Marshall, R. J. and Bleakley, A. (2011) 'Sing, muse: songs in Homer and in hospital' *Medical Humanities* 37, pp. 27–33

- Marshall, R.J. Bleakley, A. (2013) 'Lost in translation. Homer in English; the patient's story in medicine' *Med Humanit*; 39; pp 47-52
- Martin, R, and Spence, J. (1987) *New portraits for old: the use of camera in therapy*. In: Betterton R, editor. Looking on: images of femininity in the visual arts and media. London: Pandora, pp. 267–79.
- Martin, E. (2003) *The Woman in the Body: a cultural analysis of reproduction; with a new introduction*, Boston: Beacon Press
- Marvel, M. K., Epstein. R. M., Flowers, K. and Beckman, H. B. (1999) 'Soliciting the patient's agenda: have we improved?', *JAMA* 281, pp.283-287
- Mason, J. (2007, 2<sup>nd</sup> ed) *Qualitative Researching*, London, Sage Publications
- McMahon, S.B. and Koltzenburg, M. (2006) *Textbook of Pain* 5<sup>th</sup> Edition, London: Elsevier
- Melzack, R. (1975) 'The McGill pain questionnaire: Major properties and scoring method', *Pain*, 1 pp 277-299
- Melzack, R. and Wall, P.D. (1965) 'Pain Mechanisms. A new theory', *Science* 150 (699), pp.971-979
- Melzack, R. and Wall, P.D (1984) in *Textbook of Pain* , McMahon S & Koltzenburg ed (5<sup>th</sup> edition 2006) Elsevier Churchill Livingstone
- Melzack, R and Wall, P.D (2008) *The Challenge of Pain*, London: Penguin
- Merskey, H. and Bogduk, N. (eds) (1994) *Classification of Chronic Pain*, Second Edition, IASP Task Force on Taxonomy. Seattle: IASP Press pp209-214
- Meynell, K. and Skinner, A. (2005) *It's inside*, London: Marion Boyars Publishers
- Miller, D. (2005) (ed) *Materiality*, Durham & London: Duke University Press
- Miller, J. (2000) *The body in question*, London: Random House
- Morgan, W. G. (1995) Origin and history of the Thematic Apperception Test images. *Journal of Personal Assessment*, 65 (2): 237–254.
- Morley S. Psychology of pain. (2008) *Br J Anaesth*;101:25-31
- Morris, D. (1993) *The Culture of Pain*, California: University of California Press
- Morris, K. J. (1996) 'Pain, injury and first/third person asymmetry', *Philosophy and Phenomenological Research*, 56 (1) pp 125-136
- Morris, S. (2012) 'Opening the Book in Sear', in Sear H. (2012) *Inside the View*, Cardiff: Ffotogallery
- Morris, S. (2000) *Shifting Eyes: self-representation in words and images, re-reading Freud through the semiotics of C.S. Peirce, with particular reference to the work of poet H.D. and artist Claude Cahun*: University of London PhD Thesis.
- Mott, V. (1862) *Pain and Anaesthetics: An Essay, Introductory to a Series of Surgical and Medical Monographs*, Washington: Government Printing Office

- Murray, H. A. (1943) Thematic Apperception Test manual. Cambridge, MA: Harvard University Press.
- Muybridge, E. (1895) 'Gait in a case of locomotor ataxia' in Dercum, F.X. (ed) *A Textbook on Nervous Diseases*, Philadelphia: Lea
- Napenas, J. J., Nussbaum, M. L., Eghtessad, M. and Zakrzewska, J. M. (2011) 'Patients' satisfaction after a comprehensive assessment for complex chronic facial pain at a specialised unit: results from a prospective audit', *British Dental Journal* 211, E24
- Newton, K. and Rolph, C. (2003) (eds) *Masquerade, Women's Contemporary Portrait Photography*, Cardiff: Ffotogallery
- Newton-John & Zakrzewska, J. (2005), Poster Presentation: Pain Society
- Napier, D. (2003) *The Age of Immunology, Conceiving a Future in an Alientating World*, Chicago: University of Chicago Press
- Padfield, D. (2003) *Perceptions of Pain*. 1<sup>st</sup> Edition. Stockport: Dewi Lewis Publishing.
- Padfield, D., Janmohamed, F., Zakrzewska, J., Pither, C. and Hurwitz, B. (2010) 'A slippery surface, can photographic images of pain improve communication in pain consultations?', *International Journal of Surgery* 8 (2), pp.144–150
- Padfield, D. (2011) 'Representing' the pain of others' in Bell, S. and Radley, A. (eds) 'Representations of illness and disease', *Health* 15(3), pp.241–257
- Perks, R. and Thomson, A. (2010) *The Oral History Reader*, Abingdon: Routledge
- Pither, C. (2003) *Unspeakable Pain* in Padfield, D. (2003) *Perceptions of Pain*. 1<sup>st</sup> Edition. Stockport: Dewi Lewis Publishing
- Pither, C. (2011) 'Against: Pain clinic is not a place for diagnosis', *Pain News* (Winter), pp. 21
- Price, D., Greenspan, J. D. and Dubner, R. (2003) 'Neurons involved in the exteroceptive function of pain', *Pain* 106, pp.215–219.
- Punch, K. (1999) *Introduction to social research: quantitative and qualitative approaches*. London: SAGE
- Radley, A. (2009) *Works of Illness: Narrative, Picturing and the Social Response to Serious Disease*, Ashby-de-la-Zouch: InkerMen Press
- Radley, A. and Bell, S. (2011) (eds) 'Another way of knowing: Art, disease and illness experience', Special edition of *Health* 15 (3)
- Richardson, R. (1988) *Death, Dissection & the Destitute*, London: Routledge
- Richardson, R. (2000) A Necessary Inhumanity? Medical Humanities *Journal of Medical Ethics*, 26: pp 104-106

Richer, P. (1881) '*Synoptic table of the major hysterical attack – Etudes cliniques sur l'hystero-epilepsie ou grande hysteria*', Paris: Adrien Delahaye and Emil Lecrosnier cited in Hustvedt 2011 p 25

Rizzolatti, G. and Sinigaglia, C. (2008) *Mirrors in the Brain, How our minds share actions and emotions*, translated by Anderson, F., Oxford: Oxford University Press

Rizzuto, A. (1999) *metaphors of a bodily mind*, paper presented at the 88<sup>th</sup> Annual Meeting of the American Psychoanalytic Association, Washington Hilton and Towers, Washington, D.C. Submitted for publication June 2, 1999 p 535, [apa.sagepub.com](http://apa.sagepub.com) ucl library services, accessed 23rd August 2011)

Roberts, K. (2006) *Making Faces*, Norwich, Norfolk Contemporary Art Society

Robinson, J. D. and Heritage, J. (2006) 'Physicians' opening questions and patients' satisfaction', *Patient Education and Counselling* 60, pp.279-285

Rublack, U. (2002) 'Fluxes: The Early Modern Body and the Emotions', translated by Pamela Selwyn, *History Workshop Journal* 53 (2)

Sarno, J. E. (1998) *The Mindbody Prescription: Healing the Body, Healing the Pain*. New York: Warner Books

Scarry, E. (1985) *The body in pain: The Making and Unmaking of the World*. Oxford: Oxford University Press

Schopenhauer, A. (1851) *Parerga and Paralipomena*, (translated by Payne, E. F. J., 1974 edition) Oxford: Clarendon Press, 2: 634, cited Gilman 1996 p 164

Sear, H. (2002) *Twice*, London: Zelda Cheatle Press

Sear, H. (2012) *Inside the View*, Cardiff: Ffotogallery

Sear, H. (2009) *Tale*, Cardiff: g39

Sear H. (2012) from her notes '*Critical Commentary in partial fulfillment of a Doctor of Philosophy*', University of Wales, Newport, 2010, unpublished and unpaginated, cited in Chandler D. in Sear H 2012, p 126

Secton, A. (1981) 'The Big Boots of Pain' in *The Complete Poems*, Boston: Houghton Mifflin

Semino, E. (2013) 'Figurative language, creativity, and multimodality in the communication of chronic pain in two different genres' in Deignan A., Littlemore J. and Semino E. (eds) *Figurative Language, Genre and Register*, Cambridge: Cambridge University Press

Seremetakis C. N. (1996) *The Senses Still, Perception and Memory as Material Culture in Modernity*, Chicago: University of Chicago Press

Shapiro, J. (2011) 'Illness narratives, reliability, authenticity and the empathic witness', *BMJ, Medical Humanities*: Vol 37 no 2. [mh.bmj.com](http://mh.bmj.com), published by [group.bmj.com](http://group.bmj.com) (accessed 31<sup>st</sup> January 2012)

Shelley Percy, B. (2004 1<sup>st</sup> published 1820) Kessinger Publishing Co

- Sheshkin, R.B., Kelien, H. and Lowental, U. (1982) 'Assessment of children's anxiety throughout dental treatment by their drawings'. *ASDC journal of dentistry for children* (Mar-April;) 49 (2), pp.99-106
- Sontag, S. (1964) 'Man with a Pain', *Harper's Magazine*, April, pp.72-75
- Sontag, S. (1978) *On Photography*, London: Penguin
- Sontag, S. (1977) *Illness as Metaphor* (edition 1998), New York: Picador
- Sontag, S. (2003) *Regarding the Pain of Others*, London: Hamish Hamilton Ltd
- Spence, J. (1987) *Time and Light. A film about photographs*. UK Film for ILEA
- Spence J (1988) *Putting Myself in the Picture, A Political, Personal and Photographic Autobiography*, Seattle, The Real Comet Press
- Spence, J. (1995) *Cultural sniping: the art of transgression*, London: Routledge
- Spiegelman, J. M. and Miyuki, M. (1985) *Buddhism and Jungian Psychology*, Phoenix Arizona: Falcon Press
- Spivey, N. (2001) *Enduring Creation: Art, Pain and Fortitude*, London: Thames & Hudson
- Squiers, C. (2005) *The Body at Risk, photography of disorder, illness, and healing*, California: University of California Press
- Stafford, B. (1993) *Body Criticism, Imaging the Unseen in Enlightenment Art and Medicine*, Cambridge Massachusetts: MIT Press
- Stafford, B. (1999) *Visual Analogy: consciousness as the art of connecting*, Massachusetts, London: MIT Press
- Stafford, B. (2007) *Echo Objects, The Cognitive Work of Images*, Chicago, London: The University of Chicago Press
- Stafford, B. (1993) *Body Criticism, Imagining the Unseen in enlightenment Art and Medicine*, Massachusetts, London: MIT Press
- Stafstrom, C.E., Goldenholz, S.R. and Dulli, D.A. (2005) 'Serial headache drawings by children with migraine: correlation with clinical headache status', *Journal of Child Neurology* (2005) 20, pp.809–13
- Stefanatou, A. and Bowler, D. (1997) 'Depiction of pain in the self-drawings of children with sickle cell disease', *Child: Care, Health and Development* (Mar; 23) 2, pp.135-55
- Stockhausen, K. in Harrison J., (ed 2010), Programme Notes, Birmingham
- Styron, W. (1992) *Darkness Visible: A Memoir of Madness*, New York: Vintage.
- Tagg, J. (1980) 'Power and Photography: Part One, A Means of Surveillance: The Photograph as Evidence in Law' *Screen Education* 36, autumn, pp.17–55



- Tagg, J. (2009 a) *The Disciplinary Frame: Photographic Truths and the Capture of Meaning*, Minneapolis: University of Minnesota Press. P1
- Tilley, C. (1999) *Metaphor and material culture*, Oxford, Blackwell
- Todd, M. L., Higginson, T.W. (eds) (1980) *Collected Poems of Emily Dickenson*, New York, Avenal (First published 1890)
- Tolstoy, L. (1958) in Neider, C. and Tr Dole, N (eds) *Lost on the Steppe in Tolstoy's Tales of Courage and Conflict*, New York: Hanover House
- Tracey, I. (2005) 'Objectifying pain through brain imaging' in Carr, D., Loeser, J. and Morris, D. (eds) *Narrative Pain and Suffering: Progress in Pain Research and Management Vol 34*: Seattle, USA: IASP Press, p 137
- Wiech, K. and Tracey, I. (2009) 'The influence of negative emotions on pain: Behavioral effects and neural mechanisms', *NeuroImage* 47, pp.987–994
- Tracey, I. and Mantyh, P. (2007) 'The Cerebral Signature for Pain Perception and Its Modulation' in *Neuron* 55, August 2, pp 377 – 391
- Uden, A., Astrom M. and Bergenudd, H. (1988) 'Pain drawings in chronic back pain', *Spin,e* 1394, pp.389-92
- Rublack, U. (2002) 'Fluxes: The Early Modern Body and the Emotions', translated by Pamela Selwyn, *History Workshop Journal*, 53, 2.
- Unruh, A., McGrath, P., Cunningham, S. J. and Humphrey, P. (1983) 'Children's drawings of their pain', *Pain*, Dec 17 (4), pp. 385-92
- Valdas, A. (2011) 'A short History of Pain and its Treatment', in Giordano J. (ed.) *Maldynia, multidisciplinary perspectives on the illness of chronic pain*, New York: Taylor & Francis. P9
- Vallfors, B. (1985) Acute, subacute and chronic low back pain: Clinical symptoms, absenteeism and working environment. *Scandinavian Journal of Rehabilitation Medicine*, Suppl 11
- Van Dijck, J. (2005) *The Transparent Body; a cultural analysis of medical imaging*, Seattle, University of Washington Press
- Von Franz, M.L. (1974) *Shadow and Evil in Fairytales*, Zurich, Spring Publication for The Analytical Psychology Club of New York
- Wall, P. D. (2001) Review of William K Livingston 'Pain and suffering' *Medical History*, 45, pp. 134-135
- Westrin, C.G. (1970) 'Low back sick-listing'. *Acta Socio-Medica Scandinavica* 2-3, pp.127-134
- Wetherell, M., Taylor S., and Yates, S. J. (2009) *Discourse Theory and Practice: A Reader*, London, Sage

Wetherell, M. ( 2001) 'Foundations and building blocks' in Wetherell, M., Taylor S., and Yates, S. J. (eds) *Discourse Theory and Practice, A Reader*, Sage in association with The Open University, The Open University Press

Wetherell, M., Taylor, S. and Yates S, J. (2003) *Discourse as Data: A Guide for Analysis*, London: Sage in association with the Open University.

Wiech, K., Farias, M., Kahane, G., Shackel, N., Tiede, W. and Tracey, I. (2008) An fMRI study measuring analgesia enhanced by religion as a belief system, *Pain*, 139 (2), pp. 467–476.

Wildgoose, J. (2002) *The Lancet*, London, UK, vol 359

Wilkinson, M. and Robinson D. (1985) Migraine art; *Cephaalgia* Sep; 5 (3); 151-7)

Williams, S. J. (1993) *Chronic respiratory illness*. London: Routledge

Winnicott, D. W. (1974) *Playing and Reality*, London, Penguin

Wittgenstein L. (1980) *Remarks on the Philosophy of Psychology, Vol 2*, 1998 edition, Oxford: Blackwell

Woolf, V. (1967 1<sup>st</sup> pub 1930) *On Being Ill, in Collected Essays*. New York: Harcourt

Woolf, V. (2007 1<sup>st</sup> pub 1930) *On being Ill*, intro by Lee H. Ashfield, Massachussetts: Paris Press

Wright, A. (2006) Interview Alexa Wright in conversation with Keith Roberts, in Roberts, K. (2006) *Making Faces*, Norfolk, Norfolk Contemporary Art Trust p 68

Yates, P. M., Edwards, H. E., Nash, R. E., Walsh, A. M., Fentiman, B. J., Skerman, H. M. et al. (2002) 'Barriers to effective cancer pain management: a survey of hospitalized cancer patients in Australia', *Journal of Pain and Symptom Management* 23, pp.393–405

Zakrzewska, J. M. (2006) *Insights, facts and stories behind trigeminal neuralgia*, Gainesville, Florida: Trigeminal Neuralgia Association.

Zakrzewska, J. M. and Lopez, B. C. (2006) 'Trigeminal and glossopharyngeal neuralgia' in (eds) McMahon, S. B. and Koltzenburg, M. *Textbook of Pain*, 5th Edition, London: Elsevier pages 1001- 1010

Zakrzewska, J. M. (2009b) 'Facial Pain: An Update'. *Current Opinion in Supportive and Palliative Care* 3, pp.125–130

Zborowski, M. (1969) *People in Pain*, San Francisco: Jossey-Bass Inc.